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ABSTRACT

This is the final report describing a 4 year project, of which 2 years were an intensive counseling/casework demonstration with stroke patients and their families. Patients were alternately assigned to an experimental or control group; only the experimental group received intensive counseling. A comprehensive follow-up of 88 families measured differences between the groups on a newly constructed activities-of-daily-living inventory, comparisons on performance of household tasks and extent of avocational activities, and attitudes and changes in family roles. Included is a report on the outcome of the demonstration. Volume II describes, among other things, the measuring instruments which were developed. Finally, Volume III is comprised of an annotated bibliography of 26 movies about strokes, an annotated bibliography of stroke related publications, and a 316 entry regular bibliography. (Author/TL)

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EDUCATING STROKE PATIENT FAMILIES

Number 12 Volume I July 1971

CURATIVE WORKSHOP
UNIVERSITY OF WISCONSIN MILWAUKEE

CG 006 563

SIGNIFICANT FINDINGS FOR REHABILITATION AND SOCIAL SERVICE WORKERS

Findings and techniques developed	For further information see	Implications for use
An Avocational Activities Inventory was developed classifying and coding 900 avocations.	Vol. II pp. 6,7	Helps supply ideas for avocational activities to suggest to patients. Write us at address at bottom of page for free copy.
Developed an Avocational Activities Community Resource file using the above classification system. After a year we inventoried the materials we had collected in the file.	Vol. II pp. 6,7	You may wish to set up your own vertical file in which to keep information about avocational activities available in your community. Write us for a free copy of the inventory.
Developed a spot map showing the location of current and former patients.	Vol. I pp. 61, 67	You may wish to make a spot map of where your patients live and work. It gives a much better picture of transportation problems, community resources, etc.
A "family tree" form was developed to show family relationships graphically through three generations.	Vol. II p. 50	Saves writing a long narrative description and is easier to understand. Copy from page 50, Volume II.
Developed a schema to show the various ways in which patients might be able to arrange transportation.	Vol. II p. 51	Can be used as a check list when helping a patient arrange transportation. Can be copied from page 51, Volume II.
51 case reports were mimeographed and distributed to members of the rehabilitation team prior to the staffing conferences.	Vol. I p. 46	By investing a little more money in clerical work, higher priced professional personnel time can be saved.

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SIGNIFICANT FINDINGS FOR REHABILITATION AND SOCIAL SERVICE WORKERS
(continued)

Findings and techniques developed	For further information see	Implications for use
While interviewing in patient's home, counselor telephoned college student clerk-secretary who in turn secured information on community resources, etc., and informed counselor by telephone while counselor was still at patient's home.	Vol. II p. 48	Saves counselor's time. Supplies instant information for immediate decision making either in patient's home or in staff conferences.
About 70% of patients had made adaptive physical changes in the house to accommodate the impairment limitations. 15% of these adaptations were suggested by medical or paramedical professionals.	Vol. I p. 77	The counselor can be useful to severely disabled clients by knowing about and suggesting physical adaptations in the household.
Although 51% of patients said their doctor had explained their stroke condition to them, 20% could not recall anyone having explained their illness.	Vol. I p. 96	Make sure the patient is given explanation of his impairment, if this is appropriate, and if this has not already been done.
More than half the families had an annual income of less than $4,000 and less than $1,000 in savings after the stroke.	Vol. I p. 78	Sufficient health, hospitalization, and/or income protection insurance to cover catastrophic illness is of great importance to families with only moderate savings.
Men patients saw an average of 2.86 people a week; women, 2.20.	Vol. I p. 92	If your patients do not have at least this number of contacts try to arrange for someone to visit or at least telephone them regularly.
As a result of information disseminated by the counselor, experimental cases knew about and used more community resources than control cases.	Vol. I pp. 70, 71	Counselor's time can be effectively used in finding out about and informing patients about community resources.

EDUCATING STROKE PATIENT FAMILIES

Final Report

VOLUME I

Robert P. Overs, Ph.D. and John R. Healy

July, 1971

Research Department

CURATIVE WORKSHOP OF MILWAUKEE

This investigation was supported in part by Demonstration Grant No. RD-2537-P (new numbering system: 15-P-55211/5-03) from the Division of Research and Demonstration Grants, Social and Rehabilitation Service, Department of Health, Education, and Welfare, Washington, D.C. 20201.

The MILWAUKEE MEDIA FOR REHABILITATION REPORTS is designed to make available rehabilitation research information which is not easily disseminated through the usual publication channels. Some of these reports will be concerned with methodological notes and techniques which are too specific in interest to appear in regular journal publications.

Others, suitable for journal publication, will be published in the MILWAUKEE MEDIA when it appears desirable to avoid the current publication lag.

A third type of material to be published will be studies geographically related to Milwaukee and Wisconsin which, while important to that area, may have limited significance in other parts of the country.

This report, "Educating Stroke Patient Families", which is number 12 in the series, resulted from an investigation which was supported in part by Demonstration Grant No. RD-2537P (new numbering system 15-P-55211/5-03) from the Division of Research and Demonstration Grants, Social and Rehabilitation Service, Department of Health, Education and Welfare. Because of this support it is possible to disseminate this report free of charge.

This Report is published in three volumes of which this is Volume I.

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The original concept of the project is attributable to a number of people including T.S. Allegrezza, Executive Director of the Curative Workshop, Elston L. Belknap, M.D., Acting Medical Director, R. C. Danforth, M.D., Neurologist, Stroke Clinic, Mrs. I. E. Rose, Supervisor of the Home Service Department and Assistant to the Director, Miss Maxine Schuldt, R.P.T., Coordinator, Physical Restoration Program, Miss Ruth Lacey O.T.R., R.P.T., Supervisor Occupational Therapy Department, Miss Janet Lemke, R.P.T,M.A., CVA Program Coordinator, Mrs. Loretta Martin, M.S.W.,ACSW, Miss Miaja Berzins, M.A.,Supervisor, Psychology Department in addition to the Project Director.

For most of the project's duration a Staff Professional Advisory Committee comprised of the following individuals met once or twice a month:

Harold E. Cook, M.D.	Medical Director
R.C. Danforth, M.D.	Neurologist, Stroke Clinic
Mrs. I. E. Rose, O.T.R.	Assistant to the Director and Coordinator, Home Service Dept.
Miss Maxine Schuldt, R.P.T.	Coordinator, Physical Restoration Services
Miss Janet Lemke, R.P.T.,M.A.	CVA Program Coordinator
Mrs. Carol Weitkunat	CVA Program Coordinator
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Not all of the individuals listed above served during the same time period. Some were replacements for staff members who left the Agency.

Many physical therapists, occupational therapists, speech therapists, psychologists, rehabilitation counselors and social workers contributed with ideas and with specific help for experimental patients. So many helped in this process that it is impossible to identify them all by name.

Dr. George T. Wilson, Assistant Superintendent of Milwaukee Schools, Division of Municipal Recreation and Adult Education gave a great deal of help and encouragement in the development of the avocational activities materials.

Dr. Richard M. Suinn permitted us to adapt the Suinn-Feldman Rehabilitation Self-Description Scale for our use. Dr. Nathan Hurvitz permitted us the use of Marital Roles Inventory for research purposes. Dr. Peter New and Mrs. Linda George were helpful in supplying details and discussion of their work on patient-family roles.

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The help of Rev. Donovan Palmquist, Pastor of the Juneau Village Church, in this undertaking is acknowledged. Dr. Danforth's forceful support in the development of the satellite program was also instrumental in its implementation.

Sandy Cris, Judy Gross and Joy Bartusch, undergraduate students in the School of Social Welfare at the University of Wisconsin - Milwaukee, worked as volunteers and assisted subjects in completing attitude inventories.

Our thanks are due the patients who cooperated in hours of tedious questioning and completing attitude inventories.

The staff in addition to the authors, consisted of:

Mrs. Maureen Cahalan, original Project Coordinator
Miss Helen Corrigan, MSW, ACSW, Social Worker

Rehabilitation Counselors
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Many of the staff were university graduate or undergraduate students working part time. Many graduated and left the project during the four year period hence the large number associated with the project.

TABLE OF CONTENTS - VOLUME I

Chapter	Title	Page
	Significant Findings for Rehab. and Social Service Workers	
	Forward and Acknowledgements	3
	Table of Contents	5
	List of Tables	7
	Abstract	13
1	Introduction	14
	A. The Agency Setting ...14	
	B. Methodology ...16	
	C. Format ...16	
	D. Relationship of the Final Report to Progress Reports .17	
	E. Topical Arrangement ...18	
2	Characteristics of Patients and Families	19
	Patient Characteristics at Admission	24
	Patients' Measurement of Activities of Daily Living Performance.	28
	Attitude Inventories	32
	Summary and Implications	41
3	Counseling and Casework Activity	45
	A Representative Case of Intensive Counseling and Casework Effort	50
	Content Analysis of Counseling Records	53
	Summary and Implications	59
4	Satellite Program vs. Central Agency Activity Program	60
	Development of the Satellite Program Concept	61
	Summary and Implications	64
5	Controlled Study Outcome	65
	Summary and Implications	74
6	Followup Findings	75
	A. Housing ...76	
	B. Financial Status ...78	
	C. Employment Status ...80	
	D. Performance in Activities of Daily Living .81	
	E. Performance of Household Tasks ...84	
	F. Patterns of Help ...88	
	G. Social Contacts ...92	
	H. Avocational Activities ...94	
	I. Source of Information about Strokes and Community Resources ...96	
	J. Attitudes and Roles ...98	
	K. Evaluation of Stroke Experience ...105	
	L. Evaluation of Rehab. Program at Curative Workshop ...111	
	Summary and Implications	116
	Author - Subject Index	129

TABLE OF CONTENTS - VOLUME II

Chapter	Title	Page
	Table of Contents	3
	List of Forms	4
	Introduction to Volume II	5
1	Instrumentation	6
2	Miscellaneous Innovations	48
3	Research Utilization	52
4	Discussion and Conclusions	53
5	Summary and Implications	60
	Author - Subject Index	65
	Appendix	i
	Table of Contents	i
	List of Tables and Forms	ii

TABLE OF CONTENTS - VOLUME III

Section Title	Page
Introduction to Volume III	4
Annotated Bibliography of Movies on or Related to Strokes	5
Annotated Bibliography	10
Bibliography	31
Aging, Geriatrics and Retirement	31
Aphasia	33
General	34
Marriage and the Family	41
Stroke - Cerebrovascular Disease	47
Author - Index	54
Project Report Index	59

LIST OF TABLES

Number	Title	Page
	Chapter 2 - Characteristics of Patients and Families	
1	Whom the Patients Moved in With	19
2	Family Members Contributing (In Rank Order)	20
3	Availability of Adult Children for Help	20
4	Children Unable to Help Because:	21
5	The Negative Feelings of Patients and Their Families About Their Neighborhoods	21
6	Degree of Isolation of Patients and Families	21
7	Modes of Transportation Used by Patients	22
8	Patients' Capacity to Pursue Avocational Activities	22
9	Propinquity of Stroke Patient Families	23
10	Age and Sex at Admission	24
11	Type of Hemiplegia	24
12	Presence of Aphasia	25
13	Marital Status at Admission	25
14	Residence of Patients at Admission	25
15	Living Situation of Patients at Admission	26
16	Educational Level of Patients	26
17	Social Class of Patients (Measured by Hollingshead Two Factor Index)	27
18	Employment Status of Men Patients and Spouses at Admission	27
19	Employment Status of Women Patients and Spouses at Admission	28
20	MADLI Evaluations: Independent Ratings by Therapists at Admission	29
21	Agreement by Item on MADLI Evaluations at Admission	30
22	Agreement by Raters on MADLI Evaluations at Admission	31

Number	Title	Page
	Chapter 2 - Characteristics of Patients and Families - Continued	
23	Higher Ratings in Cases of Disagreement on MADLI Evaluations at Admission	32
24	Patient Goals Ranked by Patients at Admission	33
25	Patient Goals Ranked by Spouses at Admission	34
26	Husbands' Marital Roles Ranked by Husbands at Admission	35
27	Husbands' Marital Roles Ranked by Wives at Admission	36
28	Wives' Marital Roles Ranked by Husbands at Admission	36
29	Wives' Marital Roles Ranked by Wives at Admission	37
30	Patients' Roles Ranked by Patients at Admission	38
31	Patients' Roles Ranked by Spouses at Admission	39
32	Spouses' Roles Ranked by Patients at Admission	39
33	Spouses' Roles Ranked by Spouses at Admission	40
	Chapter 3 - Counseling and Casework Activity	
34	Interviews per Case	46
35	Telephone Calls per Case	47
36	Collateral Contacts per Case	47
37	Staffing Reports per Case	47
38	Counseling Reports per Case	48
39	Patient Behavior and Attitudes	53
40	Spouse	54
41	Children	55
42	Patient - Family	55
43	Counselor	55
44	Contact with Agencies	57
45	Distribution of Casework Content Categories (In Rank Order)	58

Number	Title	Page
	Chapter 5 - Controlled Study Outcome	
46	Average Number of Household Adaptations, Experimental vs. Control	65
47	Employment Status of Patients After a Stroke, Experimental vs. Control	66
48	Agreement Between Patients and Spouses on Rating of Patients on MADLI, Experimental vs. Control	66
49	Average Number of Changes in Performance of Household Tasks, Experimental vs. Control	66
50	Types of Changes in Patient Performance of Household Tasks, Experimental vs. Control	67
51	Average Number of People Seen Once a Week or More by Patients, Experimental vs. Control	67
52	Types of People Seen Once a Week or More by Patients, Experimental vs. Control	68
53	Contact with Other Stroke Patients, Experimental vs. Control	68
54	Average Number of Avocational Activities, Experimental vs. Control	69
55	Changes in Patients' Frequency of Participation in Avocational Activities After Stroke, Experimental vs. Control	69
56	Frequency of Patients Starting New Avocational Activities After a Stroke, Experimental vs. Control	70
57	Families' Knowledge of Milwaukee County Community Resources, Experimental vs. Control	71
58	Average Agreement Between Patients and Spouses on 22 Patient Description Items, Experimental vs. Control	71

Number	Title	Page
	Chapter 6 - Followup Findings	
59	Followup Interviews Completed	75
60	Residence of Patients at Followup	76
61	Living Situation of Patients at Followup	76
62	Household or Building Adaptations for Patients	77
63	Financial Situation of Patients	78
64	Sources of Income for Patients	78
65	Adjustment to Decreased Income	79
66	Employment Status of Men Patients and Spouses at Followup	80
67	Employment Status of Women Patients and Spouses at Followup	80
68	MADLI Evaluation: Independent Ratings by Patients at Followup (In Rank Order)	81
69	MADLI Evaluation: Independent Ratings by Spouses at Followup (In Rank Order)	82
70	Agreement between Patient and Spouse Ratings on MADLI at Followup (In Rank Order)	83
71	Performance of Household Tasks Before Stroke	85
72	Average Number per Family of Each Type of Change in Performance of Household Activities (In Rank Order)	86
73	Household Activities Requiring Changes in Performance After a Stroke (In Rank Order)	87
74	Who Helped the Patient? (In Rank Order)	88
75	What Forms of Help Were Given to the Patient (In Rank Order)	89
76	Whom the Patient Helped (In Rank Order)	90
77	How the Patient Helped (In Rank Order)	91
78	Number of People Seen Once a Week or More by Patients (includes spouse)	92
79	Types of People Seen Once a Week or More by Patients	93

Number	Title	Page
	Chapter 6 - Followup Findings - Continued	
80	Frequency of Contact with Other Stroke Victims	93
81	Average Number of Avocational Activities per Patient	94
82	Avocational Activities Most Frequently Mentioned by Patients (In Rank Order)	95
83	Source of Information about Strokes and Knowledge and Use of Community Resources	96
84	Milwaukee County Community Resources	97
85	Differences Between Men and Women Patients in Agreement to Patient Description Items at Followup	98
86	Differences Between Spouses of Men Patients and Spouses of Women Patients in Agreement to Patient Description Items at Followup	99
87	Differences Between Men Patients and Their Spouses in Agreement to Patients Description at Followup	100
88	Differences Between Women Patients and Their Spouses in Agreement to Patients Description at Followup	100
89	Husband Marital Roles Ranked by Husbands at Followup	101
90	Husband Marital Roles Ranked by Wives at Followup	101
91	Wife's Marital Roles Ranked by Husbands at Followup	102
92	Wife's Marital Roles Ranked by Wives at Followup	102
93	Patient's Roles Ranked by Patients at Followup	103
94	Patient's Roles Ranked by Spouses at Followup	103
95	Spouse's Roles Ranked by Patients at Followup	104
96	Spouse's Roles Ranked by Spouses at Followup	104
97	Greatest Problem Since the Stroke (In Rank Order)	105
98	Greatest Help Since the Stroke (In Rank Order)	106
99	Most Important Professional Person Since the Stroke (In Rank Order)	107
100	What is Important in Adjusting to a Stroke (In Rank Order)	108

Number	Title	Page
	Chapter 6 - Followup Findings - Continued	
101	Hindrances to Adjustment After a Stroke (In Rank Order)	109
102	Advice for New Stroke Patients and Their Families (In Rank Order)	110
103	Most Important Activity at Curative (In Rank Order)	111
104	Most Important Person at Curative (In Rank Order)	112
105	Least Important Activity at Curative (In Rank Order)	112
106	Best Experience at Curative (In Rank Order)	113
107	Worst Experience at Curative (In Rank Order)	114
108	What was Lacking at Curative (In Rank Order)	114
109	What Should be Changed at Curative (In Rank Order)	115

ABSTRACT

This project attempted to show that by focusing on the family of stroke patients,therapy gains could be maintained or increased after discharge from a rehabilitation program. Over the two year period of the demonstration 132 patients were referred to the project from the stroke clinic of an outpatient, comprehensive rehabilitation center. Half of these received intensive family counseling, the rest received the usual agency casework services and served as controls. Followup results revealed no pattern of difference between the two groups on the criterion measures: activities of daily living, household adaptations, household tasks, social contacts, avocational activities, or return to employment. The findings did reveal a rigid,sex-typed division of family roles and an increasing isolation of the family from the neighborhood. Rehabilitation efforts might best be spent in helping patients find avocational activities that approximate the lost roles and reintegrate the patients into patterns of community or neighborhood interaction. A classification and coding system for avocational activities, a community avocational activities resource file and a new activities of daily living inventory were developed.

CHAPTER 1

INTRODUCTION

The purpose of this project was to demonstrate that focusing on the family of the stroke patient as the responsible and effective unit in the patient's ultimate adjustment would result in maintaining and possibly improving patient gains after the completion of a rehabilitation program. The methodology was to provide the families of stroke patients with intensive rehabilitation counseling or casework services. The results were evaluated by comparing an experimental and control group, of which only the experimental group received the extra services. Differences in patient gains in the respective groups were measured by the Milwaukee Activities of Daily Living Inventory (MADLI), activities measurements, attitude inventories and changes in family roles.

Supplemental accomplishments were in the development of new instruments for classifying and coding avocational activities and an Avocational Activities Community Resources File. A new activities of daily living measurement device entitled, "The Milwaukee Activities of Daily Living Inventory" (MADLI) was developed. Three attitude measurement devices were constructed by adapting existing scales for use with stroke patients. The concept of community satellite centers, which would provide activity programs for stroke and other severely disabled patients, was developed and one pilot project was begun and continued for six months. A number of innovations in casework mechanics were developed and 26 movies on stroke were reviewed.

A. The Agency Setting

The Curative Workshop of Milwaukee is a multi-discipline private outpatient rehabilitation agency. During 1969, the last year in which counseling was carried on under the auspices of the project, the total Agency served 4,645 different patients in 121,322 treatment visits. There was a professional staff of 175 full time and part time workers.

The physical restoration program, which is only one of several major programs in the agency, includes medical examination and evaluation, physical therapy, occupational therapy, speech therapy, home maker training, social case work, and psychological and/or occupational evaluation when appropriate.

The Project was superimposed upon an already well established, systematic and thorough evaluation and treatment program which, under the direction of a neurologist, affords comprehensive medical, paramedical, social, psychological and occupational evaluation services as needed.

The clinic for patients who have suffered cerebral vascular accidents (CVA) is called the Stroke Clinic or CVA Clinic. This is one of several similar clinics within the agency, each organized around a specific disability. The Stroke Clinic is organized and operates in the following manner.

Referrals are received from private physicians and from the Wisconsin Division of Vocational Rehabilitation. After referral, permission is obtained from the patient's referring physician for a CVA comprehensive evaluation to be made and a special CVA referral form is sent to the physician.

When admitted, the Coordinator of the Stroke Clinic informs the patient that he will be evaluated in the various services to find out what treatment should be offered him, and that the staff will meet and discuss his treatment needs.

In every case the following evaluations of the patient are made by the staff members of the Curative Workshop:

1. A neurological examination by a neurologist to help determine differential diagnosis and make recommendations regarding treatment plans.
2. An evaluation by a physical therapist and an occupational therapist to determine potential for restoration of physical function and independence.
3. An evaluation by a social worker of the patient's social history and current social situation.

When indicated, additional evaluations are made in one or more of the following areas:

1. An evaluation of speech and hearing problems by a speech therapist to determine potential for restoration of communicative skills.

2. Psychological testing.

3. A pre-vocational evaluation to determine vocational potential.

For the following additional evaluations and/or treatment, special permission is requested from the patient's referring physician:

1. Psychiatric consultation.

2. Need for arm or leg braces and a prescription for these if appropriate.

For any additional indicated medical care including visual problems the patient is referred back to his private physician for appropriate followup.

At the initial staffing conference, reports are presented and a treatment plan developed which includes specific goals, restrictions, any additional evaluations and a date for the next staffing of the case.

The CVA Coordinator has a conference with the patient to tell him of the plan developed at the staffing conference.

The CVA Coordinator sends a letter, for approval by the referring physician, including a short summary of the evaluations of the patient, the treatment goals and plan. The referring physician approves or alters the treatment plan to be followed.

At restaffings the treatment plan is summarized. Representatives of each department report on treatment progress, discuss goals and plans for further treatment as indicated. All recommendations are communicated to the referring physician for his approval.

When the patient has reached maximum benefit from treatment, a plan for discharge from treatment is prepared. At the termination of physical therapy and occupational therapy a followup re-evaluation is scheduled, approximately three months later. At that time the patient is re-evaluated by the CVA Coordinator and other services as indicated. If further re-evaluations seem desirable they may be scheduled for periods of time varying from three months to one year, or, if indicated, treatment may be resumed.

The essential new ingredient introduced by the Project was the providing of intensive casework and/or counseling services for more clients than it was possible to serve before.

For the first six months of the demonstration a social worker provided the service. During the next year the service was provided by two rehabilitation counselors each working half time. Finally, during the last six months one of these rehabilitation counselors assumed the case load on a full time basis.

B. Methodology

This demonstration in providing intensive case work and counseling services to stroke patients was carried on for two years from January 1968 through December 1969.

Patients newly admitted to the CVA Clinic were alternately assigned to an experimental and control group by the CVA Coordinator.

As part of the evaluation portion of the Project, Three attitude inventories were administered to the patient and, if a spouse accompanied the patient, to the spouse as well. These instruments were administered to both the experimental and control groups. When possible this was done at the first or second visit to the Agency. In some instances these were completed at the patient's home.

Also, for evaluation purposes, the Milwaukee Activities of Daily Living Inventory (MADLI) was completed on each patient, usually within the first month of the treatment program.

Experimental patients were contacted by the social worker or rehabilitation counselor and offered casework and/or counseling services. The intensity of the service varied greatly among families.

Social casework evaluations were made of control cases by the Agency Social Work Department as had been standard procedure prior to the project. The social histories of the experimental patients were reported to the Stroke Clinic Staffing Conference by the Project social worker and/or rehabilitation counselor.

The Milwaukee Activities of Daily Living Inventory (MADLI) was again completed on each patient approximately at time of termination of the therapy program. The attitude inventories were re-administered to the patient and spouse at the time of the followup interview.

A preliminary followup was completed on 25 families between 10 and 22 months after discharge. A comprehensive followup of 88 families was completed between September 1970 and April 1971. Both followups were by interviews carried on in the patient's home. The preliminary followup used an unstructured approach; the final followup used a structured interview schedule.

C. Format

Where warranted, key findings from the data have been telescoped into summary and implications sheets at the end of the chapters. We have tried to present this in a form which will help to bridge the gap between research findings and existing practices. In the left hand column entitled "Summary", we have re-

capitulated in brief summary form what appear to be the key points of the data collected and the statistical analysis of the data for that chapter.

In the right hand column entitled "Implications", we have suggested what the data immediately adjacent in the left hand column imply. Although this method has its hazards in that a cause-effect relationship may be improperly assumed, we believe that it is an effective way to point out what implications for current practices and further research the findings from the research suggest. Implications are judgments made by the authors for which they are solely responsible. If the reader does not agree with the implications offerd by the authors, we hope that it will at least stimulate him to draw from the data his own implications.

The general summary for this Report, which selects the more significant findings from the chapter summaries, also uses a two column summary and implications format to more closely relate data to implications.

D. Relationship of the Final Report to Progress Reports

Three progress reports were issued on the Project as follows:

Progress Report	Date issued	Period covered by Report
First	February 1968	August 1967-February 1968
Second	February 1969	August 1968-January 1969
Third	January 1970	February 1969-January 1970

Every effort was made to include in the Final Report all information of substance which appeared in the Progress Reports. This created minor editorial problems since there is a highly specific format required for progress reports which is not directly adaptable for incorporation in a final report. Progress Report materials not included in the Final Report are preliminary developments which may be found in completed form in the Final Report; enumeration of data, based on a partial client sample, which has since been expanded; plans for future activities in the Project, some of which were not implemented; preliminary ways of organizing the data which were later discarded when better ways were developed.

In the opinion of the authors the materials appearing in the Progress Reports which do not appear in the Final Report are of use only to an investigator studying the natural history of the maturation of demonstration projects.

E. Topical Arrangement

This report is divided into three volumes. In Volume I which you are currently reading, Chapter 1, "Introduction", describes the Agency, the methodology of of the study and the structure of this report. Chapter 2, "Characteristics of Patients and Families", reports the usual demographic information about age, sex, medical diagnosis, marital status, living situation, educational level, social class and previous occupational status.

Chapter 3 describes the counseling and casework activity carried on in the Project including an enumeration of counseling input and a content analysis of counseling records. The data on clients reported in this chapter was gathered at the time of the demonstration portion of the program. There are some differences from related data collected a year later through a followup interview because the number of patients and families from whom data was collected had changed.

Somewhat autonomously, but as a natural development from the findings of the demonstration program, a plan for neighborhood activities centers emerged. This is described in Chapter 4 entitled, "Satellite Program vs. Central Agency Activity Program." The measured outcome of the differences between the experimental group (more of whom were provided intensive counseling/casework service) and the control group is presented in Chapter 5 entitled "Controlled Study Outcome." The findings of an intensive followup are presented in Chapter 6. Finally, there is an author-subject index.

In Volume II, the instrumentation developed for the Project is discussed in Chapter 1. Chapter 2 reports on miscellaneous innovations developed during the project. Research utilization is covered in Chapter 3. In Chapter 4, entitled, "Discussion and Conclusions," the data is related to findings from other studies, and general trends to be inferred from the study are suggested.

Chapter 5, "Summary and Implications," is a recapitulation, in briefer form, of the summary and implications sections appearing at the end of the relevant chapters.

A combined author-subject index for Volume II is included. An Appendix contains more detailed data on MADLI ratings, a methodological note on the reliability of the instruments, and excerpts from a content analysis of the counseling records.

Volume III includes an annotated bibliography of movies about strokes, an annotated bibliography of stroke related publications, a regular bibliograpy, an RSA-VRA-OVR Project Index and an author index.

CHAPTER 2

CHARACTERISTICS OF PATIENTS AND FAMILIES

A total of 68 patients were referred to the experimental group and a like number to the control group for a total of 136. However, two experimental patients and two control patients never actually received any therapy at the Agency so they are not included in the totals. (Sixty-six will be used as the total for both the Experimental and Control groups.)

Of the 66 experimental patients, 46 or 70% had spouses (during the course of the demonstration one client was widowed, another divorced). Including spouses, there were 242 family members, or an average of 3.67 per family. Of these, 148 or 61%, lived in the same home with the patient. Ninety-four, or 39%, lived elsewhere.

By the time the demonstration ended, five of the 66 experimental cases died for a mortality rate of 7.6% (even though 5 patients died, the original total of the group, 66, will be used throughout unless otherwise indicated). On a yearly basis this number of deaths represents a mortality rate of 3.8%, or 38 per thousand.

At the time of referral to the Agency, 49 or 74% of the experimental clients lived in their own household, and 18 of these, or 27%, had dependent children as well. Seventeen patients, or 26%, were living with other families, usually older children or other relatives. For ten of these patients (15%), the stroke had been the direct cause of moving in with another family.

Table 1: Whom the Patients Moved in With

		% of 10	% of 66
Son or daughter	8	80%	12%
Sister	1	10%	2%
Niece	1	10%	2%
Total:	10	100%	16%

There was temporary relocation for several of the clients during the course of the demonstration, such as placement in nursing home - 3; staying with relatives - 4; and hospitalization - 2. However, there was only one permanent placement to a nursing home, and this occurred after the client was widowed.

Stroke patients have specific needs beyond those of the general population and/or aged persons without major disabilities. In our rating of patient abilities using the Milwaukee Activities of Daily Living Inventory (MADLI), we found that only half the patients were considered independent in walking and transferring, and less than half in negotiating a flight of stairs. Since clients may not be safely left alone without these abilities, the problem of patient care in a household with only a spouse may range from burdensome to overwhelming. When the patient may not be left alone safely, and there is no one except the spouse in the household, the spouse can rarely get away, even temporarily. The complete absorption of the spouse in the patient's care seems a psychologically unhealthy pattern. Some friction between patient and spouse may be attributed to this.

Family members judged to have made or to be making a significant contribution to

the care and well-being of the patient were distributed as shown in the table below. In this table, and those which follow, judgments were made by the counselor at the end of the demonstration. It would have been extremely time consuming for another judge to become sufficiently familiar with the families to make these judgments. Hence the reliability of the judgments cannot be ascertained.

Table 2: Family Members Contributing (In Rank Order)

Spouse	40	34%
Daughter	21	18%
Son	19	16%
Others, nec	19	16%
Brother	5	4%
Sister	5	4%
Daughter-in-law	5	4%
Son-in-law	4	3%
Total:	118	99%

The "others, nec" category includes:

boyfriend	friends	housekeeper	nephew
brother-in-law	grandchildren	mother	niece
cousin	granddaughter	neighbor	sister-in-law
			wife's parents

The fate of the patient and the family are closely dependent upon general changes in society. While the patients' needs could be met by several members of the large kinship family of the past, in the current small nuclear family the full responsibility often falls heavily on one person, usually the spouse. Adult children, pursuing marriage and job opportunities, frequently move out of the community and are not available to help. The availability of adult children for help is indicated in the following two tables.

Table 3: Availability of Adult Children for Help

		% of 14	% of 66
Cases where adult children live in the same house (includes some in the same house but separate apartment)	11	79%	17%
Cases where adult children live separately but in the same neighborhood	3	21%	5%
Total:	14	100%	21%

In those cases where help was not forthcoming from children of the patients, the primary reason for the lack of help was judged to fall in the following categories (in rank order):

Table 4: Children Unable to Help Because:

		% of 40	% of 66
Children moved away	12	30%	18%
Children's work	11	28%	17%
Deficient role definitions for sons	8	20%	12%
Alienated from parents	6	15%	9%
Parent's inability to accept help	3	8%	5%
Total:	40	101%	61%

The patients and their families expressed their feelings about the neighborhoods in which they lived as indicated in the table below. These are overlapping categories; some families expressed feelings in several categories.

Table 5: The Negative Feelings of Patients and Their Families about Their Neighborhoods

		% of 51	% of 66
Complained of neighborhood changing	9	18%	14%
Neighbors unfriendly and don't care	12	24%	18%
Patients did not want to get involved	21	41%	32%
Patients were proud of not wanting to get involved	9	18%	14%
Total:	51	101%	77%

Families were classified according to type and degree of neighborhood isolation (in rank order from least to most). In five cases either the patient was not living with his family of the situation was not known well enough to be classified.

Table 6: Degree of Isolation of Patients and Families

		% of 61	% of 66
Not isolated (had interdependent contact with more than one family in neighborhood)	6	10%	9%
Marginally isolated (had interdependent contact with one family in neighborhood)	3	5%	5%
Isolated from neighbors but maintained so social contacts outside neighborhood, including institutional ties, such as churches and lodges	16	26%	24%
Isolated from neighbors with no other contacts other than family and work group	36	59%	55%
Total:	61	100%	93%

Nor can stroke families frequently rely upon neighbors for help. Our stroke families often moved into new neighborhoods and did not have friends nearby who they could call upon for help. Of the families who had continued to live in the same neighborhood, nine complained that the people had changed to the point where they themselves felt like strangers.

To maintain social interaction with other people usually involves getting the patient out of the home to go to where people and activities are. Transportation is important in meeting patient needs for more social interaction.

Table 7: Modes of Transportation Used by Patients (in order of most "normal" to least "normal")

		% of 54	% of 66
Drives car	6	11%	9%
Uses public transportation	2	4%	3%
Can ride in car or taxi only	37	69%	56%
Can ride in Handicab only	9	17%	14%
Total:	54	101%	82%

As a minimum, transportation elements are: the type of vehicle, the method of payment, the social role of the driver, and the social role of the attendant if one is required. We have developed a comprehensive schema for considering most of the possible ways to arrange transportation (see Volume II, Chapter 2).

That only one patient in the experimental group was employed is probably attributable to the severity of their disabilities; an unemployment rate of less than 3% prevailed in Milwaukee during 1968 and 1969. A judgment that 14 or 21% are potentially employable includes such options as sheltered employment, home-bound employment and selective placement.

An evaluation of the patients' capacity to pursue avocational activities divides them into two groups:

Table 8: Patients' Capacity to Pursue Avocational Activities

Able to pursue avocational activities outside of home. These patients have the motivation and would enjoy the interaction with other people provided that transportation could be made available.	32	48%
Able to pursue avocational activities at home only.	34	52%
Total:	66	100%

Major Factors Impeding Pursuit of an Avocational Activity (In Rank Order)

Physical condition	35	35%
Transportation	26	26%
Lack of motivation	22	22%
Family attitude	12	12%
Lack of know-how	3	3%
Lack of equipment	3	3%
Total:	101	101%

Is it geographically feasible for stroke patient families to cooperatively help each other? A spot map was developed and the table below shows the propinquity of the families. The median number of blocks which stroke patients lived from the nearest other stroke patient was 8 blocks. By inspection the modal distance was 10 blocks. The range was 2 to 40. Except for the five families who were within two blocks of another stroke family, transportation by vehicle would usually be required for contacts between families. This is without considering the problems of compatibility between families, ability to help, etc.

Table 9: Propinquity of Stroke Patient Families

Number of blocks from closest stroke family	Number of stroke families within this distance
2	5
3	6
4	8
5	3
6	5
7	6
8	2
9	7
10	12
13	3
14	1
15	4
16	1
19	1
40	2

Patterns of isolation initiated by demographic changes are reinforced by what we view as maladaptive behavior. The stroke family urgently needs occasional help from friends and neighbors but is often reluctant, or unable, to secure it. For some of the families, isolation was merely a continuation of the family mode of living in which, except for occupational contacts, there was very little interaction with people outside the family prior to the stro It would be a major attitudinal change for these families to seek more in action with outside people after the stroke.

Good adjustment for the stroke patient means maintaining the highest possible level of social interaction with others, and participating in activities. Participating in activities is more important as a path to increased social interaction than as a goal in itself. That the patient and his family do not always see this as a goal does not nullify the fact that to manage they have to depend upon other people. To do this they have to make friends and set up a reciprocity system whereby the helping person benefits from the exchange, either gratitude or renumeration.

What the other people may be called upon to do for the stroke patient and his family is not very demanding. The kind of assistance the family needs is for someone to attend the patient for an hour so the spouse can go shopping, take the patient out for a drive, or take him to and from an activity once a week, etc. Divided among four relatives, friends or neighbors this amounts to each person contributing about half a day of time once a month. This does not seem excessive.

In addition to the scarcity of informal helping patterns in the community, there is no institutionalized pattern of community help. In England there is the week-end hospital where the patient may go for a few days to give the spouse a rest from his arduous role of eternal attendant. Some nursing homes in the United States are beginning to provide this service.

Patient Characteristics at Admission

The following ten tables summarize information about the age, sex, type of disability, marital status, type of residence, living situation, educational level, social class and occupational status of both Experimental and Control patients at the time of their admission to the Agency.

About 58% of the total number of patients were men. Strictly by chance, the Control group had a 2:1 ratio of men to women while the Experimental group was evenly divided.

Many of the patients were past retirement age but a sizeable number (44%) were in the age bracket 40-61 where employment or homemaking would still be a major concern. This was especially true in the Experimental group where over half the men (56%) were in the 40-61 age range, many with dependents.

Table 10: Age and Sex at Admission

Age	Experimental				Control				All Patients	
	Men		Women		Men		Women			
65 and over	10	31%	16	47%	20	46%	8	36%	54	41%
62-64	3	9%	4	12%	8	18%	-	-	15	11%
40-61	18	56%	13	38%	14	32%	13	59%	58	44%
39 and under	1	3%	1	3%	2	5%	1	5%	5	4%
Total	32	99%	34	100%	44	101%	22	100%	132	100%

The cases were about evenly divided between types of hemiplegia. Slightly more than half (54%) had their right side affected.

Table 11: Type of Hemiplegia

Type	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Right Hemiplegia	18	56%	23	68%	21	48%	9	41%	71	54%
Left Hemiplegia	14	44%	11	32%	19	43%	12	55%	56	42%
Mixed Hemiplegia	-	-	-	-	4	9%	1	5%	5	4%
Total	32	100%	34	100%	44	100%	22	101%	132	100%

Slightly less than half of the patients (44%) suffered from some degree of aphasia. A somewhat higher percentage of women had speech difficulties than men (48% to 41%).

Table 12: Presence of Aphasia

	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Aphasic	13	41%	17	50%	18	41%	10	45%	58	44%
Non-Aphasic	19	59%	17	50%	26	59%	12	55%	74	56%
Total	32	100%	34	100%	44	100%	22	100%	132	100%

The great majority of the people (74%) were married. A higher percentage of women were widowed than men (25% to 8%). Relatively few patients were divorced or single.

Table 13: Marital Status at Admission

Status	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Married	27	84%	19	56%	36	82%	16	73%	98	74%
Widowed	1	3%	10	29%	5	11%	4	18%	20	15%
Divorced	2	6%	1	3%	-	-	1	5%	4	3%
Single	2	6%	4	12%	3	7%	1	5%	10	8%
Total	32	99%	34	100%	44	100%	22	101%	132	100%

The great majority of patients lived in a private house, or two family flat. Somewhat more Experimental patients lived in apartments than Control cases (15% to 8%) but the number is small for either group.

Table 14: Residence of Patients at Admission

Type of Residence	Experimental		Control		All Patients	
House	39	59%	51	77%	90	68%
Flat	16	24%	7	11%	23	17%
Apartment	10	15%	5	8%	15	11%
Trailer	1	2%	2	3%	3	2%
Nursing home	-	-	1	2%	1	1%
Total	66	100%	66	101%	132	99%

Most (68%) of the patients lived with their spouse only, grown children, or other relatives. About 12% lived alone and another 19% had dependent children still in the home. In both these last cases the Experimental group had a higher percentage of cases: 20% vs. 5% living alone and 27% vs. 11% with dependent children.

Table 15: Living Situation of Patients at Admission

Type of Situation	Experimental		Control		All Patients	
With spouse only	21	32%	28	42%	49	37%
With spouse and children under 18	17	26%	7	11%	24	18%
With spouse and children over 18	6	9%	17	26%	23	17%
Alone	13	20%	3	5%	16	12%
With children over 18	3	5%	6	9%	9	7%
With relatives	4	6%	4	6%	8	6%
With spouse and relatives	1	2%	-	-	1	1%
With children under 18	1	2%	-	-	1	1%
Nursing home	-	-	1	2%	1	1%
Total	66	102%	66	101%	132	100%

Nearly half the clients(48%) had only an elementary school education. About a fifth (22%) had some high school and the remaining 30% finished high school. The Experimental and Control groups seem equally matched with regard to educational level.

Table 16: Educational Level of Patients

Level	Experimental				Control				All Patients	
	Men		Women		Men		Women			
College Graduate	4	13%	2	6%	1	2%	1	5%	8	6%
Some college	1	3%	2	6%	1	2%	2	9%	6	5%
High School Grad.	3	9%	6	18%	10	24%	6	29%	25	19%
Some High School	8	25%	9	26%	7	17%	4	19%	28	22%
Elem. School Grad.	7	22%	8	24%	17	41%	6	29%	38	30%
Some Elem. School	9	28%	7	21%	5	12%	2	9%	23	18%
Total	32	100 %	34	100%	41*	98%	21*	100%	128*	100%

* missing data on four cases

About three quarters of the cases were in the lower two classes. This is very close to the distribution found by Dr. Artes (Artes, 1967-stroke). Eighty percent of his sample were from Class IV and V. Less than 10% were in the upper two professional clases. The Experimental and Control groups seem equally matched on this variable.

Table 17: Social Class of Patients (Measured by Hollingshead Two Factor Index)

Class	Experimental		Control		All Patients	
I	3	5%	2	3%	5	4%
II	3	5%	2	3%	5	4%
III	9	14%	11	20%	20	11%
IV	25	38%	27	48%	52	43%
V	26	39%	14	25%	40	33%
Total	66	101%	56*	99%	122 *	100%

*missing data on ten cases

The two tables below show that roughly equivalent proportions of husbands and wives worked in the families of the two groups at the time of admission to the Agency. The figures for the men experimental patients and their spouses are a little higher but not significantly so. In about a third of the families, the husband had already stopped working by the time of the stroke, and the wife worked in only about a third of the families.

Table 18: Employment Status of Men Patients and Spouses at Admission

	Men Patients						Wives of Men Patients					
Before Stroke	Experimental		Control		All men Patients		Experimental		Control		All Spouses	
Full-time	23	72%	25	58%	48	64%	7	27%	5	14%	12	20%
Part-time	-	-	2	5%	2	3%	2	8%	3	9%	5	8%
Not working	9	28%	16	37%	25	33%	17	65%	27	77%	44	72%
Total	32	100%	43	100%	75	100%	26	100%	35	100%	61	100%

Table 19: Employment Status of Women Patients and Spouses at Admission

	Husbands of Women Patients						Women Patients					
Before Stroke	Experimental		Control		All Cases		Experimental		Control		All Cases	
Full-time	11	61%	10	67%	21	64%	9	26%	7	33%	16	29%
Part-time	-	-	1	7%	1	3%	3	9%	1	5%	4	7%
Not working	7	39%	4	27%	11	33%	22	65%	13	62%	35	64%
Total	18	100%	15	101%	33	100%	34	100%	21	100%	55	100%

Patients' Measurement of Activities of Daily Living Performance

The patient's performance in activities of daily living was measured by an inventory especially designed for this purpose. This is entitled the Milwaukee Activities of Daily Living Inventory (MADLI). The rationale for the scale, instructions to raters, scoring procedures, and the inventory itself are presented in Volume II, Chapter 1.

The patient, spouse, therapist and counselor were each asked to evaluate the patient's ability to perform nine activities of daily living. The therapist's rating was considered the best indicator of remaining physical ability, but the patient and spouse would know best what the patient actually did at home. The different ratings were then compared to see what items, and which raters, produced the most agreement. When there were disagreements, the ratings were examined to see if one of the raters consistently gave the higher scores. Tables 20 to 23 give the figures for each item and for each pair of raters. The findings are summarized below.

A total of 117 patients were evaluated by the therapists. The same general pattern prevailed for both men and women, and Experimental and Control cases. Experimental men, however, were rated as somewhat less independent on the items of transferring, walking, and stairs (from 10% to 20% fewer independent ratings) than the other groups.

The majority of all clients were seen by the therapist as being able to eat and use the dial phone without assistance. Only about half were rated as independent in the activities of walking and transferring and less than half the cases were considered independent in use of stairs. Thus at least half of the clients could not be left alone for even short periods of time and their activities were practically limited to those in the home. This restricts their vocational and avocational possibilities considerably. It also places an extra burden on the spouse and significant others who care for the patient.

Those items which had fewer independent ratings were the same ones to have less inter-rater agreement. Transferring and stairs had two of the lower rates of inter-rater agreement. Usually it was the patient who disagreed with the others and gave himself a higher score than the others gave him. When there was a disagreement in the combined items of transferring, walking, and stairs, the patient tended to give himself a higher score than the spouse or therapist by a 4:1 ratio. Accepting help in these activities is conceding disability,

and thus ego damaging. These are also activities where the spouse would not feel justified in taking a chance if there is any doubt regarding the ability of the patient to perform safely. Since they are so crucial to all other activities, disagreements could lead to conflicts in family planning.

On the three items of eating, dressing and dial phone the exact opposite occurred. Here it was the therapist who tended to give a higher rating than the patient himself, or the spouse, by a 3:1 ratio. This could indicate that carryover from the ideal conditions of the Workshop (where the therapist evaluates the patient) to the practical realities of the home is slight. Perhaps this is because families are not taking full advantage of the assistance devices available. On the other hand, it may mean that the spouse is not willing to take the extra time to let the patient do these himself.

The following table shows that the therapists' ratings fall into three groups. On the items of eating and dial phone, the vast majority of clients were rated as independent. On transferring, dressing, walking , and push button phone, about half were independent. On wheelchair, stairs and leg braces, less than half of those rated were independent. The Experimental men tended to be ranked lower than the other groups on most items.

Since ability to use stairs is usually necessary if a patient is to be able to do any outside activities, a dependent rating on this item alone could seriously limit the patient's vocational and avocational possibilities. For about half the cases, it was the therapist's judgement that they could not safely transfer or walk independently, This would preclude their being left alone, even for short periods.

Table 20: MADLI Evaluations: Independent Ratings by Therapists at Admission *

Item	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Eating	22	88%	29	97%	35	88%	19	91%	105	91%
Dial phone	17	74%	24	83%	26	70%	16	76%	83	75%
Walking	12	46%	20	62%	25	66%	13	62%	70	60%
Dressing	13	52%	18	60%	24	62%	9	43%	64	56%
Transferring	9	38%	14	45%	22	58%	12	57%	57	50%
Stairs	7	30%	10	40%	17	49%	8	47%	42	42%
Push-button Phone	3	50%	3	75%	3	50%	2	40%	11	52%
Leg brace	2	40%	2	33%	3	50%	3	33%	10	38%
Wheelchair	3	38%	-	-	4	36%	1	12%	8	24%
Total No. of independant ratings	88	53%	120	62%	159	64%	83	58%	450	60%

* Percentages are based upon the number of patients actually rated on that activity. Not all patients were rated on each activity.

Use of the phone, eating and walking all had more than 70% agreement among raters. Stairs, transferring and dressing were harder to rate and agreement varied from 59% to 67%. Use of the wheelchair, push-button phone and leg braces were not rated often enough to compare directly with the others. The experimental men were the hardest cases to agree on. This proved true for all items and by about the same amount (10-15%). Perhaps this is related to the fact that experimental men received more dependent or semi-dependent ratings than the other groups. In the appendix (Vol. II) there are nine tables which show the agreement between each pair of raters on each of the nine items.

Table 21: Agreement by Item on MADLI Evaluations at Admission *

Item	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Dial phone	55	71%	59	75%	30	75%	19	91%	163	75%
Eating	52	61%	69	79%	33	75%	16	80%	170	72%
Walking	58	66%	66	75%	29	72%	15	71%	168	71%
Stairs	45	56%	47	69%	28	78%	15	83%	135	67%
Transferring	45	52%	58	66%	25	71%	11	61%	139	61%
Dressing	40	47%	57	65%	28	70%	14	67%	139	59%
Push-button Phone	5	64%	5	100%	3	100%	1	33%	14	74%
Leg braces	9	60%	14	70%	5	83%	4	50%	32	65%
Wheelchair	13	54%	7	47%	7	64%	3	33%	30	51%
Total No. of agreements	322	58%	382	71%	188	74%	98	71%	990	67%

* Percentages are based upon the number of comparisons actually made on each item. Not all patients were rated by each rater on every item.

From the table below it appears that the patients are usually inclined to agree with the opinions of others concerning their ability. Conversely, the spouses tend to disagree more often than any other rater. We must remember, however, that the spouses have the most contact with, and ultimate responsibility for, the patients so it is their evaluations which most accurately reflect what the patient actually does, or is allowed to do.

The patient-therapist pair averaged 83% agreement ranging from a high of 87% on use of dial phone by women clients to a low of 66% on dressing by male patients. The therapists are, of course, all female.

The patients and spouses concurred 70% of the time. Transferring had the least agreement (only 56%) and use of phone by women had the most (100%). What husband doesn't know if his wife can use the phone or not?

The therapist-counselor pair managed to agree on 68% of the comparisons, ranging from only 50% on transferring(clients usually remained seated during counseling session) to 82% on eating.

The patient-counselor average of 64% agreement, ranged from a low of 50% on dressing (never observed) to a high of 78% on use of phone (counselor made frequent phone contacts).

The spouse and therapist agreed only 60% of the time. Dressing was the hardest for them to agree on (only 44%) and walking was the easiest (73%).

The spouse and counselor had the lowest rate of agreement (57%), helped along by the figure of 41% on dressing (again never actually observed by counselor). However, they did agree 77% of the time on walking.

Table 22: Agreement by Raters on MADLI Evaluations at Admission *

Raters	Experimental				Control				All Patients	
	Men		Women		Men		Women			
Pt.-Sp.	56	63%	32	71%	60	77%	24	73%	172	70%
Pt.-Th.	66	65%	98	77%	80	78%	45	68%	289	73%
Pt.-Co.	64	59%	93	68%					157	64%
Th.-Co.	70	62%	102	72%					172	68%
Sp.-Th.	34	46%	27	63%	48	64%	29	73%	138	60%
Sp.-Co.	32	49%	30	68%					62	57%
Total No of agreements	322	58%	382	71%	188	74%	98	71%	990	67%

* Percentages are based upon the number of comparisons actually made by each pair of raters. Each pair did not rate all patients on all items.

The following table reveals a general tendency for the patient to give himself a higher rating than the others give him if there is a difference of opinion. It also shows that the spouse tends to give a lower rating than the others in the same circumstances. What it does not reveal are certain definite trends on specific items.

On the three items most important for deciding whether the patient can be left alone - transferring, walking, and stairs, the patient gave the higher rating in case of disagreements by a 4:1 ratio. These are items where it is embarrassing to be helped, yet difficult for the observer not to feel an obligation to help, if there is a chance of falling and injury. More effort might be devoted to getting families to use ramps, grab bars, railings, etc. in the home, when this is feasible.

On the other three items rated often enough to compare - eating, dressing and dial phone - the exact opposite occurred. Here, the patient gave himself a lower rating than the therapist gave him by a 3:1 ratio. The spouse also gave the patient a lower evaluation than did the therapist on these items (3:1 ratio). These activities are not actually performed at the Agency for the therapist to evaluate but are simulated under ideal conditions. The results indicate that carry-over to the home may be rather low. The conditions in the Agency might be made more realistic and a greater effort might be made to get the families to

avail themselves of aids for these activities (special utensils, clothes, etc.).

Table 23: Higher Ratings in Cases of Disagreements on MADLI Evaluations at Admission *

Pair A B	Men Patients A>B		Women Patients A>B		All Patients A>B	
Pt.-Sp.	32	63%	14	64%	46	63%
Pt.-Th.	30	52%	29	58%	59	55%
Pt.-Co.	26	58%	14	32%	40	45%
Th.-Co.	20	47%	17	42%	37	45%
Sp.-Th.	28	42%	10	37%	38	40%
Sp.-Co.	12	36%	7	50%	19	40%

* Percentages are based upon the actual number of disagreements made by each pair of raters. Each pair did not make the same number of disagreements.

Attitude Inventories

At the time of their admission to the Agency the patients and their spouses were asked to complete several attitude inventories. These are described in detail in Volume II, Chapter 1: Instrumentation. The following ten tables summarize the responses to the goals and the roles inventories.

In general the responses revealed a rather conservative, traditional view of the family and familial roles. The husband was described as the support of the family and the wife was seen as the homemaker. Companionship was recognized as a, if not the, main function of marriage (Blood and Wolfe, 1960 - family; Centers, 1971- family) and there were carefully delineated spheres of responsibility for household chores. Social activities such as visiting, getting out, or learning a new activity were consistently rated low. The main area of disagreement between husbands and wives seemed to be in the area of household tasks. Evidently the stroke upset the division of labor established over years of marriage and there seemed to be resistance to re-defining the respective roles of the spouses.

When a husband was the patient, both he and his wife agreed that the primary role of each was to be a companion to the other. The husband usually desired to return to employment (unless already retired) and the wife agreed. They agreed that the husband should help himself as much as possible and do his exercises so as to speed his recovery. The wife emphasized the exercises more than the husband.

The wife's duties were seen as helping her husband whenever she could, while continuing as a homemaker. Neither partner desired the employment of the wife. Neither placed a high value on visiting, entertaining friends, getting out of the house or representing the family in the community.

There was some disagreement on the question of household tasks. Neither seemed

to want to do the tasks together. The husband expected the wife to take over some of his duties while he took over some of hers. The wife, however, was not anxious to take over his duties or have him do hers. Perhaps quite realistically, his efforts at helping would just create more work for her.

When a wife was the patient, both partners agreed that their primary role was that of a companion to the other. They both felt the husband should support the family and help his wife when she required it, although she should help herself whenever possible. Neither wanted the wife employed and neither emphasized visiting, entertaining, or getting out once in a while.

They disagree on the sharing of household jobs. The wives ranked a return to homemaking as their most important role while the husbands seemed to be less confident that this would happen. The husbands stressed doing their own duties while taking over some of the wife's. The wives did not want to relinquish any of their own duties or take over any of the husband's.

The two main goals of the patients were to regain the use of their affected arm and resume the performance of their former role - working or homemaking. However, the men patients were far more anxious to return to work than the women patients were to resume homemaking. Neither men nor women patients gave much emphasis to social or educational goals: visiting, getting out of house, learning activities, reading and writing.

Table 24: Patient Goals Ranked by Patients at Admission

	N=47. Men Patients		N=34. Women Patients		N=81. All Patients	
	1st or 2nd	3rd - 5th	1st or 2nd	3rd- 5th	1st or 2nd	3rd- 5th
Regain use of arm	36%	32%	53%	15%	43%	25%
Return to work/ resume homemaking	51%	8%	12%	15%	34%	11%
Be able to walk	15%	34%	29%	38%	21%	36%
Be like old self again	13%	34%	26%	35%	18%	34%
Get out of house	17%	32%	18%	44%	17%	37%
Be independent in self-care	19%	32%	12%	35%	16%	33%
Regain speech	15%	8%	12%	9%	13%	9%
Learn some activity	13%	30%	12%	23%	12%	27%
Be able to read and write	8%	21%	18%	12%	12%	17%
Be able to visit and entertain	8%	21%	9%	18%	8%	20%

The only goal the spouses felt was important to the patient was to regain the use of the affected arm. None of the others was given a high ranking by more than a fifth of the spouses. The spouse did not feel that the patients were as anxious to resume work or homemaking as the patients themselves said they were. Only half as many spouses gave resume work/homemaking as high a ranking as the patient did.

Table 25: Patient Goals Ranked by Spouses at Admission

	N=35, Spouses of Men Patients		N=17, Spouses of Women Patients		N=52, Spouses of All Patients	
	1st or 2nd	3rd-5th	1st or 2nd	3rd-5th	1st or 2nd	3rd-5th
Regain use of arm	66%	11%	53%	29%	61%	17%
Be independent in self-care	20%	49%	23%	47%	21%	48%
Be like old self again	20%	43%	23%	18%	21%	35%
Be able to walk	20%	20%	29%	12%	23%	17%
Return to work/ resume homemaking	26%	17%	6%	65%	19%	33%
Regain speech	20%	9%	35%	6%	25%	8%
Get out of house	14%	49%	6%	6%	11%	35%
Learn some activity	6%	46%	12%	47%	8%	46%
Be able to visit and entertain	3%	20%	12%	18%	6%	19%
Be able to read and write	3%	20%	-	35%	2%	25%

The husbands in our sample saw their main roles as being a companion, supporting the family, and doing their own work around the house. Husbands who had a stroke were more likely to give greater emphasis to the companionship role than to the other two. Non-patient husbands gave about equal emphasis to all three roles. Men with strokes were more likely to give a low rating to the two roles concerning housework than non-patient husbands.

Table 26: Husbands' Marital Roles Ranked by Husbands at Admission

	N=32 Husband a Patient			N=15 Husband Not a Patient			N=47 All Husbands		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th 9th
Be a companion to wife	62%	19%	19%	47%	40%	13%	57%	25%	17%
Do own jobs around house	56%	19%	25%	53%	47%	-	55%	28%	17%
Support of family	31%	6%	62%	47%	33%	20%	36%	15%	49%
Help with housework if needed	25%	44%	31%	13%	80%	7%	21%	55%	23%
Practice the family religion	16%	53%	31%	7%	53%	40%	13%	53%	34%
Manage the family finances	6%	56%	37%	20%	60%	20%	11%	57%	32%
Make the decisions	-	78%	22%	7%	33%	60%	2%	64%	34%
Represent family in the community	3%	53%	44%	-	40%	60%	2%	49%	49%
Be a sexual partner to wife	-	47%	53%	7%	13%	80%	2%	36%	62%

The wives wanted their husbands to be a companion and a provider for the family. Wives of stroke patients were more likely to emphasize the companionship aspect. None of the other six roles received much attention. Whereas the husbands, both patients and non-patients, had ranked doing their own jobs around the house highly, the wives did not seem to feel the same way. Hardly any wives indicated that they wanted, or expected, the husbands to be helping them with the housework.

Table 27: Husbands' Marital Roles Ranked by Wives at Admission

	N=27, Wife not a Patient			N=11, Wife a Patient			N=38, All Wives		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6rd	7th-9th
Be a companion to wife	81%	15%	4%	64%	18%	18%	76%	16%	8%
Support the family	67%	7%	26%	73%	9%	18%	68%	8%	24%
Do own jobs around the house	15%	59%	26%	27%	45%	27%	18%	55%	26%
Practice the family religion	15%	63%	22%	18%	54%	27%	16%	60%	24%
Help with the housework if needed	7%	37%	56%	18%	54%	27%	11%	42%	47%
Be a sexual partner to wife	11%	41%	48%	9%	45%	47%	11%	45%	47%
Manage the family finances	4%	63%	33%	-	63%	34%	3%	63%	34%
Make the decisions	-	59%	41%	-	63%	37%	-	63%	37%
Represent the family in the community	-	48%	52%	-	45%	55%	-	45%	55%

The husbands placed the most importance on their wives' being a companion to them. Next came her homemaking function. Husbands of patients were inclined to give more importance to the homemaking than were the other men. There was little indication that the husbands felt the wife should help support the family, even when the husband had suffered a stroke.

Table 28: Wives' Marital Roles Ranked By Husbands at Admission

	N=32, Husband a Patient			N=13, Husband Not a Patient			N=45, All Husbands		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th
Be a companion to husband	62%	28%	9%	69%	23%	8%	64%	27%	9%
Be the homemaker	34%	47%	19%	61%	23%	15%	42%	40%	18%
Practice the family religion	28%	47%	25%	15%	61%	23%	24%	51%	24%
Help support the family	22%	16%	62%	15%	23%	61%	20%	18%	62%
Manage the family finances	16%	59%	25%	8%	61%	31%	13%	60%	27%
Make the final decisions	6%	47%	47%	8%	46%	46%	7%	47%	47%
Be a sexual partner to husband	6%	34%	59%	8%	46%	46%	7%	38%	55%
Represent the family in the community	6%	72%	22%	-	85%	15%	4%	75%	20%

The wives feel that their most important roles is that of a companion. Wives with a stroke gave less importance to companionship than non-stroke wives. After companionship came homemaking and practicing the family religion. The wives, like their husbands, gave little thought to helping support the family.

Table 29: Wives' Marital Roles Ranked by Wives at Admission

	N=28, Wife Not a Patient			N=11, Wife a Patient			N=39, All Wives		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th
Be a companion to husband	79%	21%	-	54%	36%	9%	72%	26%	2%
Be the homemaker	43%	53%	4%	54%	18%	27%	46%	43%	10%
Practice the family religion	39%	50%	11%	36%	64%	-	38%	54%	8%
Help support the family	18%	32%	50%	9%	9%	82%	15%	26%	59%
Manage the family finances	14%	68%	18%	9%	36%	54%	13%	59%	28%
Make the decisions	4%	68%	29%	18%	64%	18%	8%	66%	26%
Be a sexual partner to husband	4%	50%	46%	9%	54%	36%	5%	51%	43%
Represent the family in the community	-	57%	43%	9%	54%	36%	3%	56%	41%

Nearly all the patients felt that it was most important for them to help themselves as much as possible. Two-thirds of the women felt it was important for them to resume homemaking but only one-third of the men were planning to return to work. While nearly one-half of the men patients said it was important for them to help the spouse with her duties, only 10% of the women patients felt it was important for them to help their spouse when he needed it. In fact, fully 82% of the women patients said this was the least important of the nine roles. Evidently, the men patients were more open to role changes than the women patients.

Table 30: Patients' Roles Ranked by Patients at Admission

	N=36, Men Patients			N=11, Women Patients			N=47, All Patients		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th 9th
Help self as much as possible	72%	17%	11%	64%	18%	18%	70%	17%	13%
Resume work/ home-making	31%	33%	36%	64%	36%	-	38%	34%	28%
Help spouse with his/her duties	44%	33%	22%	9%	9%	82%	36%	28%	36%
Practice exercises	28%	61%	11%	36%	54%	9%	30%	59%	11%
Talk over problems with spouse	8%	69%	22%	9%	82%	9%	8%	71%	19%
Try to understand if spouse gets upset	8%	56%	36%	9%	45%	45%	8%	53%	38%
Try to get out of house	6%	50%	44%	9%	64%	27%	6%	53%	40%
Entertain self while spouse is busy	3%	61%	36%	9%	82%	9%	4%	66%	30%

The spouses gave first importance to the patients' doing their exercises. The patients, especially the men patients, disagreed with this. Both patients and spouses agreed that the patient should help himself, but the spouses did not rate this as highly as the patients did. The greatest discrepancy between patients and spouses came on the area of household tasks. The men, whether patients or spouses, expected the wives to help them with their duties, and they were willing to take over some of hers. However, the wives, whether patients or not, were not interested either in taking over the husband's duties or having him help her.

Table 31: Patients' Roles Ranked by Spouses at Admission

	N=30 Spouses of Men Patients			N=14 Spouses of Women Patients			N=44 Spouses of All Patients		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th
Practice exercises	77%	20%	3%	43%	57%	-	66%	32%	2%
Help self as much as possible	43%	47%	10%	50%	29%	21%	43%	47%	14%
Resume work/ homemaking	37%	17%	47%	21%	71%	7%	32%	34%	34%
Help spouse with his/ her duties	13%	30%	57%	43%	21%	36%	23%	27%	50%
Talk over problems with spouse	10%	60%	30%	14%	50%	36%	11%	57%	32%
Try to understand if spouse gets upset	13%	60%	27%	7%	29%	64%	11%	50%	39%
Try to get out of house	7%	67%	27%	7%	57%	36%	7%	64%	29%
Entertain self when spouse is busy	-	77%	23%	14%	57%	29%	-	77%	23%

The patients wanted their spouses to help them when needed and to take over those duties which they could no longer do. The men patients gave relatively more importance to both of these than did the women patients. The women patients were far more inclined to give a high rating to"understanding when they get upset" and"talking over problems"than were the men.

Table 32: Spouses' Roles Ranked by Patients at Admission

	N=35 Men Patients			N=11 Women Patients			N=46 All Patients		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th
Help patient when needed	86%	8%	6%	54%	27%	18%	78%	13%	9%
Take over patient's duties	60%	31%	9%	45%	27%	27%	56%	30%	13%
Help patient with exercises	31%	49%	20%	27%	45%	27%	30%	48%	22%
Try to understand if patient gets upset	3%	71%	26%	36%	64%	-	11%	69%	19%
Talk over problems with patient	6%	74%	20%	27%	45%	27%	11%	67%	22%
Support the family	6%	17%	77%	18%	27%	54%	9%	19%	72%
Entertain patient	6%	63%	31%	-	64%	36%	4%	63%	33%
Encourage patient to visit	-	71%	29%	-	82%	18%	-	74%	26%

All the spouses agreed that it was most important for them to help the patient whenever necessary. Husbands of women patients also gave high ranking to taking over the patient's duties but the wives of men patients did not rate this highly. They preferred to stress helping the patient with his exercises.

Table 33: Spouses' Roles Ranked by Spouses at Admission

	N=30 Spouses of Men Patients			N=15 Spouses of Women Patients			N=45 Spouses of All Patients		
	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th	1st-2nd	3rd-6th	7th-9th
Help patient when needed	73%	27%	-	80%	20%	-	75%	24%	-
Take over patient's duties	33%	57%	10%	60%	33%	7%	42%	49%	9%
Help patient with exercises	40%	50%	10%	20%	67%	13%	33%	55%	11%
Try to understand if patient gets upset	20%	60%	20%	13%	60%	27%	18%	60%	22%
Talk over problems with patient	13%	70%	17%	13%	47%	40%	13%	62%	24%
Encourage patient to visit	10%	63%	27%	7%	73%	20%	9%	67%	24%
Support the family	10%	20%	70%	7%	33%	60%	9%	24%	67%
Entertain patient	-	50%	50%	-	40%	60%	-	50%	50%

Characteristics of Patients and Families: Summary and Implications

Summary	Implications
Demographic and Physical Characteristics	
41% of the patients were 65 and over.	Employment is not usually an important consideration for this group.
About half had right hemiplegia.	This appears to be a medically representative group of stroke patients.
Almost half were aphasic.	This greatly increased the data collection problem in this project.
Three-fourths were married. Only one lived in a nursing home; all others lived in a house, apartment, or trailer.	The difficulties of institutionalization were not a problem for this group.
Over two-thirds lived with spouse only, grown children or other relatives.	Most patients were tied into a family living style of life.
The stroke had been the direct cause of moving in with another family for 16%. Only 12% lived alone.	
Nearly half had only an elementary education.	Their characteristic mode of adjustment is probably strongly influenced by limited formal education and modest financial resources.
Nearly three-fourths were in the lower 2 social classes.	
At the onset of the stroke about two-thirds of the men and one-third of their spouses had been working, regardless of which had the stroke.	The accomodation to the stroke syndrome seemed more difficult for those with immediate pre-stroke employment than for those who were retired prior to the onset of the stroke.
About half of the patients were rated as independent in walking and transferring and less than half in use of stairs.	At least half of the patients could not be left alone and activities were practically limited to the home.
Patients lived from 2 to 40 blocks apart. Median - 8 blocks; mode - 10 blocks.	Except for the 5 families who were within 2 blocks of another stroke family, transportation by vehicle would usually be required for contacts between families.

Characteristics of Patients and Families - Continued

Miscellaneous Characteristics as Observed and Analyzed by the Project Rehabilitation Counselor

Summary	Implications
Modes of Transportation (N=54 families)	
11% of patients drove cars 4% used public transportation 69% could ride in car or taxi only 17% could ride in Handicab only	As reported in many other studies, lack of adequate transportation severely limits activities for these families; to maintain social interaction with other people usually involves getting the patient out of the home to go where people and activities are.
Avocational Activities (N=66 families)	
Patients were limited in pursuing avocational activities because of: Physical condition 35% Transportation 26% Lack of Motivation 22% Family Attitude 12% Lack of know-how 3% Lack of equipment 3%	This particular group of patients was not amenable to substituting avocational activities for work or homemaking as meaningful goals.
Assistance from Children (N=40 families)	
Children unable to help because: Children moved away 30% Children's work 28% Deficient role definitions for sons 20% Alienated from parents 15% Parents' inability to accept help 8%	A substantial portion of Project counseling time was devoted to resolving some of these conflicts.
Degree of Isolation (N=61 families)	
Not isolated 10% Marginally isolated (contact with more than one family in neighborhood) 5% Isolated from neighbors but contacts with formal organizations outside neighborhood 26% Isolated from neighbors - contacts with family and work group only 59%	The fate of the patient and the family are closely dependent upon the increasing alienation of urban society. Although recent studies report a higher degree of social interaction in cities than previously believed, this has rarely been on a neighborhood basis. Stroke families need the physical and social interaction help which physically adjacent neighbors can give most effectively.

Characteristics of Patients and Families - Miscellaneous Characteristics - Continued

Summary	Implications
Attitudes toward their Neighborhoods (N=51 families)	
Complained of neighborhood changing 18% Neighbors unfriendly and don't care 24% Patients did not want to get involved 41% Patients were proud of not wanting to get involved 18%	The attitudes of stroke patients and their families towards neighbors are extremely dysfunctional. As indicated above, they desperately need the help which neighbors can give most effectively.

Characteristics Based on Responses to Standardized Attitude Inventories

On responses to questions about goals and marital roles, both patient and spouse reflected a conservative, traditional view of family and familial roles: husband as provider; wife as homemaker.	The values of society are more important than either medical condition or personality characteristics in the adjustment outcome of stroke families. The values by which this older group of individuals, with limited formal education, guide their lives are traditional and conservative and may no longer be characteristic of younger age groups with more formal education.
Companionship was selected as the main function of marriage.	Every effort should be made to avoid separating couples for purely "practical" reasons such as finances, easier patient care, etc.
Two main goals of the patients were to regain use of affected arm and resume performance of former roles: working for men homemaking for women	Emphasis should be on resuming the former role in spite of loss of affected arm.
Both wanted the husband to return to work unless he was already retired.	
Men patients were more anxious to return to work than women patients to resume homemaking. Neither desired the employment of the wife.	The logic of role reversal is in conflict with attitudes stemming from society's sanctioned values. It is unlikely that they can be changed through counseling.
When wife was the patient, she ranked return to homemaking as her most important role.	

Characteristics of Patients and Families - Characteristics Based on Responses to Standardized Attitude Inventories - Continued

Summary	Implications
Neither placed a high value on visiting, entertaining friends, or getting out of the house.	The logic of reciprocity in mutual help and social interaction is not supported by favorable attitudes towards it.
There were sharply separated spheres of responsibility for household chores, with disagreement between responses of husbands and wives over tasks.	Strokes upset the division of labor established over years of marriage and there is resistance to redefining the respective roles of the spouses.
Neither wanted to do the tasks together. The wife was not anxious to take over his duties nor to have him do hers.	The logic of reshuffling roles and duties is not supported by attitudes favorable to this.

CHAPTER 3

COUNSELING AND CASEWORK ACTIVITY

The counseling and casework demonstration portion of the project covered a two year span, from January 1, 1968, through December 31, 1969. Three individuals shared the counseling responsibility during this period. A social worker worked full time from January 1, through July 31, 1968. Two rehabilitation counselors worked part time from August 1, 1968 through July 31, 1969. One of these rehabilitation counselors then worked full time from August 1, through December 31, 1969.

The counselor/caseworker role on this Project required three major competencies:

1. Empathetic counseling
2. Efficient case management
3. Research orientation which included recording data with sufficient detail and accuracy for research purposes

This is an extremely difficult work role because the demands of each of three work role elements compete with each other. Despite a variety of checks and controls more deficiencies occurred in the research orientation than in either of the other work elements.

As judged by the many telephone calls patients and spouses made to the counselors and by very favorable comments patients made to the followup interviewer concerning the counselor who spent the most time on the project, the counseling was empathetic.

Judged by the recorded reports of counselor assistance through verbal interaction involving such techniques as ventilation, appropriate response to expressed feelings, appropriate interpretation supported by some observed improvement in attitude and behavior change on the part of patient, spouse and children, some effective counseling took place.

Judged by the recorded number and kinds of practical assistance in finding community resources to meet the needs of patients and their families, some effective case management also took place.

Adequately recording the kind and extent of counselor behavior turned out to be more of a problem than anticipated. It had been a planned strategy of the project to avoid involving the counselors in so much research oriented record keeping that they would be unable to interact empathetically with patients and families. Neither did we wish to divert their energies from vigorous and innovative case management. This goal was accomplished, but at the expense of less adequate documentation of counselor input than we had anticipated. For instance, one counselor frequently worked evenings and weekends in meeting patient crisis needs for transportation to get medical attention, resolving acute intrafamily frictions, securing housekeeper care, etc. That we failed to keep a completely detailed and accurate record of this activity is a built-in hazard of action research.

The counseling focused on those families most needing help. The need for help was evidenced by the many telephone calls received from the families by the counselors. The counseling centered around basic family problems crucial to

the welfare of the patient, although sometimes not directly involving him. A report on A Representative Case of Intensive Counseling Effort is shown on one of the following pages.

A total of 286 interviews were held, 372 telephone calls and 336 collateral contacts made; 328 counseling reports were prepared of which 51, or 15.5% were mimeographed and 277, or 84.5% , typed.

The figures above underrepresent the amount of counseling input because the counselors sometimes neglected to record counseling activities. In respect to amount of counseling received, the families may be divided into four groups.

Amount of counseling effort:	N	% of 66
Intensive counseling (5-17 interviews)	21 (8.9 apiece)	31.8
Short term counseling (2-4 interviews)	31 (2.8 apiece)	47.0
Information getting interviews (1 interview)	11	16.7
No contact	3	4.5
Total	66	100.0

The number of interviews for the 63 families interviewed ranged from 1 through 17 (Mean 4.54, Median 3.03). Twenty-one, or 32% received intensive counseling with the number of interviews ranging from 5 through 17. Thirty-one or 47% received short term counseling with 2 to 4 interviews apiece. Eleven or 17% were interviewed only once for orientation purposes or to secure a social history for the diagnostic staff conferences. Three patients, or 5% dropped from the stroke clinic program before they could be interviewed. In summary, the bulk of the counseling was carried on with a hard core of 21 families.

Table 34: Interviews per Case

	No. of interviews	No. of cases	
Intensive counseling	17	1	
	13	5	
	12	1	
	10	2	
	9	1	
	8	2	
	6	4	
	5	5	
	Total: 188 interviews	21 cases	Mean 8.9
Short term counseling	4	9	
	3	7	
	2	15	
	Total: 87 interviews	31 cases	Mean 2.8
Information getting interviews	1	11	
	Total: 11 interviews	11 cases	Mean 1.0

Table 35: Telephone Calls per Case

No. of Telephone Calls	No. of Cases
45	1
36	1
32	1
17	2
15	1
13	1
12	4
11	1
10	1
9	1
8	1
7	5
6	4
4	4
3	5
2	7
1	7
Total: 372 Telephone calls	47 cases

Table 36: Collateral Contacts per Case

No. of Collateral Contacts	No. of Cases
32	1
27	1
22	1
16	1
15	2
14	2
12	4
11	1
10	1
9	2
8	2
7	3
6	1
5	1
4	4
3	4
2	4
Total: 336 collateral contacts	35 cases

Table 37: Staffing Reports per Case

No. of Staffing Reports	No. of cases
6	1
5	2
4	7
3	7
2	12
1	24
Total: 113 staffing reports	53 cases

Table 38: Counseling Reports per Case

No. of Counseling Reports	No. of Cases
12	1
11	4
10	3
9	4
8	4
7	4
6	4
5	6
4	6
3	16
2	9
1	2
Total: 328 counseling reports	63 cases

Most of the counseling effort was devoted to the 21 families (32%) with the most problems. Because of the severity of the problems, the counseling task became one of retarding the deterioration of the situation rather than making gains. This effort may be measured more reasonably in terms of the negative things which did not happen to the patient than in terms of positive things which did. Accordingly, such indices as keeping the patient alive, sane and out of a hospital or nursing home may be the most pertinent measure of what was accomplished.

A substantial amount of counselor time was consumed in preparing patient social histories and presenting them at Stroke Clinic Staffing conferences. Attendance at all Stroke Clinic Staffings and Interdepartmental Staffings was an additional time consuming requirement in being part of the rehabilitation team.

Giving information about the physical and psychological effects of a stroke was an integral part of counseling when the patient or family indicated that this was of concern to him or them. This method varied from the original intent to give formal didactic training in group sessions. Giving information as an integral part of a group counseling approach is well described in Straus, et.al. (1967- stroke). Giving this information as the need arises in counseling seemed to us the preferred practice if enough individual counseling time is available. As an example, the counseling approach used to help a wife handle changes in the patient's personality is indicated in the case of Mr. X:

> Mr. X, the patient, found the subject of money an especially sensitive one. He refused to believe that they were short of funds, and interpreted his wife's efforts to get him to help her make financial decisions as harassment, and her complaints of the difficulties of living within their income as a direct attack on his ability as a provider. Financial discussions usually ended with a tearful wife and a highly agitated patient.

The counselor discussed the situation with the wife and explained how a stroke can affect psychological functioning, decrease powers of memory and concentration, make working with figures difficult, and cause a lack of self-esteem due to loss of employment and feelings of helplessness. This was suggested as part of the origin of Mr. X's unrealistic attitude and erratic behavior. The counselor suggested that Mrs. X discuss financial matters with her adult son or daughter.

Outcome: Mrs. X no longer tried to discuss money with her husband. He kept his small check from the Agency Education and Adjustment Program and that satisfied him.

A Representative Case of Intensive Counseling and Casework Effort

The Patient's Situation	Counseling Action
Mrs. Y first suffered a stroke in April of 1968. When released from the hospital, her left arm and leg were slightly weak. Within four weeks, she was back in the hospital with a second stroke, the worst effects of which left her left arm and leg paralyzed and her speech impaired. Doctors termed her stroke as a bilateral lesion which affected her ambulation, judgement and emotions. Mrs. Y had difficulties remembering things besides being unable to control her emotions. She cried frequently and sometimes laughed uncontrollably and generally seemed depressed.	
The stroke also had its effect on Mr. Y, Mrs. Y's 59 year old husband. Mr. Y at the time of Mrs. Y's stroke was employed as a purchasing agent at a manufacturing company. Mrs. Y up to the time had been generally healthy, with the exception of periodic nosebleeds and high blood pressure, and was herself employed as a secretary for a local physician. There had been a strong psychological inter-dependence between the two marked by their close companionship and mutual decision-making. This factor made the period following Mrs. Y's stroke a particularly stressful one for Mr.Y (whose own health was poor) in that he suddenly faced: 1) responsibility for the care of his previously self-sufficient wife; 2) those responsibilities which had been his wife's; 3) the loss of her companionship and 4) financial worries.	
During the summer succeeding her hospitalization, the Y's attempted to adjust to the conditions brought on by Mrs Y's stroke. Mr. Y hired a housekeeper to care for her due to her judgement and balance problems. Mrs. Y's physician referred her to the Home Services Occupational Therapy Dept of the Curative Workshop for home therapy sessions. She was also receiving home care from the Visiting Nurse Association. In August the Home Services Dept. referred Mrs. Y to the Workshop as a regular out-patient where she began intensive therapy and counseling sessions.	Rehabilitation Counselor began counseling sessions.
In November, 1968, Mrs Y's Counselor referred her to the DVR for financial help to enable her to participate in the Workshop's Special E A Program. During the nine months she participated in the program, she always seemed	Counselor referred Mrs. Y to the Division of Vocational Rehabilitation for financial aid. Then referred her to Evaluation and Assessment

The Patient's Situation	Counseling Action
depressed and apathetic especially when Mr. Y was hospitalized and her daughter suffered a nervous breakdown. Further complicating her condition was the housekeeper situation. The housekeeper who had been with the Y's since that summer and whom Mrs. Y liked, left them in November. The counselor went to great lengths to find another housekeeper for Mrs. Y before the first one left. None of her attempts were successful until finally, Mrs. Y's sister found a housekeeper which the Y's could afford. Technically, then the major need had been met satisfactorily, but Mrs. Y disliked the particular housekeeper saying that she was unclean and did not give her proper care. She also felt that her husband sided with the housekeeper. Ultimately Mrs. Y was persuaded to put up with her simply because another housekeeper at a reasonable price would have been impossible to find. To further supplement the housekeeper's care, Mr. Y requested that the counselor engage the services of a visiting nurse for the duration of his hospitalization in the spring	Program. Counselor's attempts to find companion housekeeper included: 1. WSES (Milwaukee) 2. WSES (Waukesha) 3. Waukesha Training Center 4. Curative Vocational Training Center 5. Personal Friends 6. Marquette Medical School Counselor engaged services of Visiting Nurse for Mrs. Y.
All the problems seemed to have a bearing on Mrs. Y's progress (or lack of it) in the E A Program. By July of 1969, she still had not come out of her depressed state and remained inactive, and apathetic in the workshop. At this time, she was dropped from the program primarily because of its imminent discontinuance. Mrs. Y, however, took it as a personal rejection of herself and was emotionally shaken by her discharge.	
In August, 1969, Mr. Y died suddenly of a heart attack. Mrs. Y went into such a state of shock, that hospitalization was necessary. When her mental state failed to improve, her counselor began to look for a suitable nursing home for her. One other complication had arisen at this time which added th Mrs. Y's mental state. Her son had undergone a divorce sometime previous to Mr. Y's death. She learned of the divorce soon after Mr. Y's death. Mrs. Y's counselor carerully sellected a suitable nursing home and also persuaded Mrs. Y's brothers to rent rather than sell her home, thus giving Mrs. Y the psychological advantage of knowing she still had a home. In addition, all the while the counselor was searching for a nursing home, she also conferred with Mrs. Y's lawyer regarding Mrs. Y's financial worries.	Counselor's attempts to locate a suitable nursing home for Mrs. Y: 1. Call State Board of Health 2. Conference with an operator of a nursing home 3. Former Public Health Physician called 4. Visit with Mrs Y to a Resident Home 5. Consultation with brothers Counselor conferred with Mrs. Y's attorney regarding financial matters.

The Patient's Situation	Counseling Action
Mrs. Y entered the nursing home in the fall of 1969 where she presently is residing. The counselor made regular visits "for supportive reasons." Mrs. Y apparently was still suffering from acute despondency although she was physically comfortable and undergoing Physical Therapy twice a week. She was referred by her counslor to the Adult Day Care Program at the Curative Workshop, and was accepted. Although no transportation was available, the counselor continued to negotiate with Mrs. Y's brothers and the administration at the nursing home to solve that problem.	Counselor made regular visits to Mrs. Y in nursing home. Counselor referred Mrs. Y to Adult Day Care Center at Curative Workshop. Counselor continued to try to arrange for transportation.

Content Analysis of Counseling Records

As indicated earlier, 327 case reports were prepared describing the social situation of the 63 families interviewed and the interaction of the counselor with them. The following section presents a content analysis of the material found in these records and also material found in the case records of 53 control cases. Categories as indicated below were developed on an empirical basis after reading the records. The counselors were not asked to arrange the data in their reports under these categories.

The intent of this section is to show the kind of patient behavior, attitudes and family relations to be found in counseling these families, and how the counselor/caseworker interacted with the patient and families. These are estimates only. As indicated earlier, much counseling activity was underreported. There was no attempt to measure, by using two or more judges, the accuracy with which items were selected from the records and assigned to categories. We believe the methodology used suffices, however, to give a rather concrete picture of what was going on in the families and with the counseling. A more detailed analysis is presented in the Appendix in Volume II.

In the tables following, the categories into which items were judged to belong are presented in the left hand column. To the right of this are columns showing the number of items found in the counseling records judged to fit in that category. The number in the experimental cases is given first, then the control cases, then the total. In the right hand column we have presented examples of the material in the respective categories.

Table 39: Patient Behavior and Attitudes

	Experimental N= 327	Control N= 53	Total N= 380	Example
Positive changes	20	0	20	Miss X seemed more relaxed after talking with the counselor. She had been receiving crank telephone calls for some time which upset her emotionally, and she was afraid to use the telephone. Now she will call friends and relatives and is more able to deal with the crank caller when the need arises.
Deteriorating changes	26	4	30	The patient is depressed and feels the termination of therapy at Curative is ominous. It has forced consideration of the possibility that she will never regain use of her arm, a prospect she has not fully faced before.
Unrealistic attitude	9	5	14	Mr. R refuses to consider any alternative to his present job even though a return may be unrealistic. He considers any suggestions for vocational training as "pushing".

Table 39: Patient Behavior and Attitudes - Continued

	Experimental	Control	Total	Example
Post stroke avocational activities	35	37	72	Mrs. M was inclined to take up a renewed interest in the Eagles Drum and Bugle Corps in which both she and her husband were very active previous to the stroke. Their children were band members and Mrs. M acted as secretary and also chaperon on band trips. After the stroke Mrs. M felt she could no longer aid the organization and therefore took no active part. At the time of follow-up Mrs. M has again become involved in the organization and expressed a great sense of accomplishment to the interviewer over this activity.
Total	90	46	136	

Table 40: Spouse

	Experimental	Control	Total	Example
Dependency on spouse	19	1	20	Mr. L is quite dependent on his wife and does not want her to return to work even though it would aid them financially. Mr. L suffers from dizzy spells and feels that his wife must be with him at all times to help him if he blacks out. Aside from that, he also feels that a wife's position should be that of homemaker.
Evidence of spouse resentment	11	6	17	Tension arises because the patient is often dissatisfied with her husband's housework and he is unable to leave the house. He stated that confinement to the house was their greatest single problem, and mentioned that neither was hesitant about expressing the irritation resulting from this.
Adjustment of spouse to patient n.e.c.	24	0	24	Mrs. E is quite ingenious in forcing her husband to do things on his own. For example he has always enjoyed eating and she uses this as an incentive to put forth greater effort in walking, by insisting that he come to the table unassisted.
Total	54	7	61	

Table 41: Children

	Experimental	Control	Total	Example
Type of help planned and given patient and spouse by children	23	1	24	Apparently the son and daughter living at home contribute at least some of their salaries to the family resources. They have also been trying to help the patient with her speech. They have bought flash cards and are trying to teach her the English alphabet again (the patient's native tongue is Chinese).
Total	23	1	24	

Table 42: Patient - Family

	Experimental	Control	Total	Example
Solutions to problems reached by patients and families	17	0	17	Mr. K has always been unable to handle finances well and so he has allowed his son to take care of them. Although the patient does not always like this situation, it has helped him to get out of debt and stay out of debt.
Moving plans of patient and spouse	14	0	14	Mr. G and Mrs. G moved from their former apartment to an apartment in a municipal public housing development for the elderly, as they could not continue to afford their former apartment on his pension.
Total	31	0	31	

Table 43: Counselor

	Experimental	Control	Total	Example
Instances of counseling	14	0	14	The Counselor explained to the R's that their marital problems are not due to their father's presence in their household. Rather, they existed before the patient moved in with them and they simply used the patient as a rationale for not getting along. Once this truth was acknowledged by the couple they developed a much better attitude in their relationship to the patient.

Table 43: Counselor - Continued

	Experimental	Control	Total	Example
Advice given patient and spouse by counselor	16	1	17	Mr. C threatened to catch a bus to go to the tavern. Counselor advised that the family let him. "He may make it, which is all to the good. Otherwise, he'll come home and you'll hear no more about it." Subsequently it was learned that he did catch the bus and went to the tavern. His friends were not there. He successfully rode the bus but it was a frightening experience and he has not tried to do so again nor has he tried to leave home.
Instances of counselor case management	14	3	17	The counselor referred the M's to the Medicare Program for assistance in obtaining payments. This has reduced the family medical costs. The counselor also referred Mr. M, the patient, to the Agency's Activities program. This has given the patient a chance to interact with people in a similar situation and thus alleviate some of his fears. Mrs. M now has a chance to be alone and relax while he is at the program, thus diminishing some of the tension in her life.
Other ways in which counselor helped	9	0	9	The counselor elected to set aside part of each home visit just to listen to the patient, even though it may not be possible to understand her, as the counselor feels that the patient's awareness and judgment far exceed her ability to communicate and that this is intensifying her feelings of worthlessness and rejection.
Subjects discussed by counselor, n.e.c.	25	0	25	The counselor talked about the problems that had arisen in the family structure and ways to ease the tension. She also talked about ways to overcome the patient's fear of falling. Since the patient did not like to do housework, the counselor talked of alternatives to keep the patient busy. She offered the patient counseling about the patient's negative feelings about the patients writing and typing skills. Finally, she discussed the family's future plans for the husband's retirement, travel and moving to an apartment.
Total	78	4	82	

Table 44: Contact with Agencies

	Experimental	Control	Total	Example
What physician and therapists, etc. told patients to do	24	1	25	"talk as much as possible" - speech therapist; "exercise the body through walking" - physical therapist; "become involved in avocational activities" - occupational therapist; "reduce weight through dieting" - family doctor
Patient and spouse reactions to Curative Workshop program	14	9	23	At the followup interview, Mrs. S reported that Mr. S, the patient, had died some time ago, but Mrs. S still wanted to thank the people at Curative Workshop for being so kind and helping. She expressed deep gratitude for all the things that Curative Workshop had done for their family. Since her husband's death she had recommended two individuals to the Curative Workshop for services. * * * The spouse did not want anything more to do with Curative Workshop. He felt that Curative Workshop had almost ruined his wife - her feet hurt so badly from working on that cold, concrete floor. He also stated that they asked too many personal questions.
Other agencies patient or family had contacted	10	3	13	The Church of Later Day Saints assists the patient in getting to and from services and social events. They have also indicated that if the patient ever needs money they will offer a helping hand.
Total	48	13	61	

The following summary table shows the content categories of most concern as evidenced by the frequency of their appearance in counseling records of patients in the experimental group. In general, there was a fairly even distribution of responses among content categories within a relatively narrow range of 3% to 11%. The post stroke avocational activities category topped the list.

Table 45: Distribution of Casework Content Categories (In Rank Order)

Content Categories	Content Item Count	
Post stroke avocational activities	35	11%
Deteriorating changes	26	8%
Subjects discussed by counselor	25	8%
Adjustment of spouse to patient, n.e.c.	24	7%
What physician and therapists told patient to do	24	7%
Type of help planned and given to patient by children and spouse	23	7%
Positive changes	20	6%
Dependency on spouse	19	6%
Solutions to problems reached by patient and family	17	5%
Advice given patient and spouse by counselor	16	5%
Moving plans of patient and spouse	14	4%
Instances of counseling	14	4%
Instances of counselor case management	14	4%
Patient and spouse reactions to Curative Workshop Program	14	4%
Evidence of spouse resentment	11	3%
Other agencies patient or family had contacted	10	3%
Unrealistic attitudes	9	3%
Other ways in which counselor helped	9	3%
Total:	324	98%

Counseling and Casework Activity: Summary and Implications

Summary

Project counselor/caseworker roles:
1. Empathetic counseling
2. Efficient case management
3. Research orientation toward data gathering

Implications

The demands of these three compete with each other. Research record keeping came out a bad third. Consequently, the amount of counselor input is consistently underreported.

Counseling Effort: (N=66 families)

Intensive counseling: 31.8%,
188 interviews with 21 families
for a mean of 8.9 interviews

The bulk of the counseling was carried on with a hard core of 21 families. The most empathetic and resourceful counselors are required with this group.

Short term counseling: 47.0%,
87 interviews with 31 families
for a mean of 2.8 interviews

More cognitively oriented and less empathetic counselors may function well with this group.

Information getting interviews: 16.7%,
1 interview with each of
11 families.

From our experience it is likely that counselor aids could to this information getting, freeing counselors for actual counseling.

Number of interviews for 63 families ranged from 1 through 17, mean 4.54, median 3.03.

286 interviews were held
372 outgoing telephone calls and
336 collateral contacts were made.
328 counseling reports were prepared
of which:
51 (15.5%) were mimeographed
227 (84.5%) were typed

Mimeographing cases and distributing them so that they can be read before the staffing conference can save valuable and expensive professional time.

113 reports on 53 cases were prepared for staffing conferences.

Some of this is rewriting, condensing and editing previous counseling reports and can be done by college level secretaries.

Content categories of most concern as judged by a content analysis of counselor records.

Counselors, at least in recording their activities, were most concerned with patient behavior and attitudes, closely followed by reporting counseling actions.

Patient Behavior and Attitudes	90	28%
Counselor.....	78	24%
Spouse.....	54	17%
Contact with Agencies.....	48	15%
Patient-Family.....	31	10%
Children.....	23	7%

CHAPTER 4

SATELLITE PROGRAM vs. CENTRAL AGENCY ACTIVITY PROGRAM

By the time the demonstration program was completed in December, 1969, the Project staff had a broad perspective and strong feelings about the problem of the patients' social needs

While very helpful, individual casework is expensive and consumes highly skilled professional time.

Could structural changes be made in the system which would permit a larger number of patients to be handled by fewer professional personnel and which would eventually help the patients to handle more of their own problems at the community or neighborhood level?

There seemed to be at least two major directions in which programs could proceed: central agency activity programs or decentralized satellite programs. The first of these would be to increase activity programs in large centralized rehabilitation centers such as Curative Workshop. We judged advantages and disadvantages to be as follows:

Advantages:

1. An activity program is already operating in the Agency and merely need be enlarged.
2. Additional therapeutic assistance would be readily available.

Disadvantages:

1. Accomodating the needs of all the potential clients would be an enormous task requiring a tremendous addition to the building and staff.
2. Transportation costs would be astronomical.
3. Clients might become over dependent upon the Agency.

A model exists in an activities program for severely disabled patients with little or no work potential. It has been conducted at the Agency since December, 1967. Activities have included recreational, educational, personal development activities and a small amount of subcontract work. Starting with thirteen patients this has grown to a total of 50 by June, 1971.

In September, 1970 the availability of additional funds made possible the enlargement of the program. In November, the Project Rehabilitation Counselor was hired as an additional staff member. The program emphasis changed in the direction of giving a great deal of responsibility for developing and carrying out the program to the patients themselves.

The change in the program emphasis, toward a greater patient responsibility, began with a discussion between the Supervisor of the Activities Program and the Project Director on how to solve patient transportation problems. The central idea became one of treating handicapped people as responsible adults, who, given the opportunity, could resolve their problems of living in the same manner as other people. There was also reinforcement from the strongly held position of the Supervisor of the Social Work Department that the patients themselves should plan the program and not have it prescribed for them.

Among ways of implementing this policy, patients have supervised other patients,

kept and summerized attendance and production records and planned programs.

A second option was to develop satellite centers in neighborhoods where activity groups could be carried on by the patients with minimal professional supervision.

Advantages:

1. Hopefully this would encourage friendship networks to develop on a neighborhood basis so that patients would meet their mutual help and social needs on their own without the intervention of an outside agency.
   An intervening step to make this possible would be the establishment of satellite centers which would run activities programs to get patients acquainted with each other and accustomed to planning their own programs and meeting their own needs.
2. Building costs would be minimal because programs would be housed in existing church buildings, activity rooms in housing projects, and similar facilities.
3. Transportation costs would be greatly reduced because clients would have shorter distances to travel from their homes to neighborhood facilities.
4. It would re-establish a sense of neighborhood community with strong social bonds and patterns of mutual sharing.

Disadvantages:

1. Coordination problems would arise as a result of a central rehabilitation agency working with a number of smaller neighborhood facilities partly manned by volunteers.
2. At least at first, the programs would have to start out on a part time basis with facilities much more limited than those which could be offered by the central rehabilitation agency.
3. It would be more difficult to refer patients to the central rehabilitation agency for needed therapeutic services.

The Project Policy Committee, acting in an advisory capacity, played a key role in developing guidelines and encouraging individual social work student interns and Agency staff members both in the direction of developing satellite programs and in steering the direction in which the Agency Activity Program developed. It was a sounding board for the expression of differing points of view including the medical, paramedical, social work, rehabilitation counseling and sociological. It linked the ends towards which we were striving with the means we thought should be used to get there.

Development of the Satellite Program Concept

The idea of a satellite program dates back at least as far as November, 1966 when the Acting Medical Director of the Curative Workshop and the Neurologist of the Stroke Clinic started a club, at their church, for stroke patients. There was a membership of 25-30 stroke patients and their spouses. A committee of 15 church members participated in this as a service project. A Physical Therapy Supervisor and an Occupational Therapy Supervisor from the Curative Workshop originally served as advisors.

From March through October, 1970, in regular monthly meetings, the Project Policy Committee explored the possibilities of setting up neighborhood satellite programs. A spot map was developed showing the geographic location of current

Curative Workshop patients who might benefit from the development of neighborhood satellite centers. This revealed several potential clusterings on the North and Northwest sides of the city.

Working under the direction of the Social Work Field Instructor, with assistance from the Project Coordinator and Project Director, a Lutheran clergyman of fifteen years experience, who was serving a student social work internship in the Agency, surveyed the community for possible community facilities interested in, and suitable for, a satellite program. Using the spot map as a guide, the churches and public housing projects in the area of the city in which the most patients were located were covered first. The Social Work Student completed a preliminary survey of 22 sites including 14 churches and 2 housing projects.

Following this survey, a team consisting of this Student, the Supervisor of the Activity Program in the Agency and the Coordinator of the Stroke Clinic, made 8 on-the-site visits of selected facilities to inspect the suitability of the premises for physically impaired patients. A completed survey for showing this methodology is included in Volume II.

Six facilities were very interested in cooperating on the project and had excellent facilities. One church donated $100 to the Agency Activities Program and pledged $1,000 to develop a half-day-a-week activities program at their church for the severely disabled when the Agency was ready to provide the leadership in this.

In summary, following the discontinuance of the intensive counseling/casework demonstration, further demonstration work in behalf of stroke patients was not dropped but the emphasis was changed in the direction of developing group social, recreational, and educational activities, preferably closer to the neighborhoods in which patients live.

The ultimate goal is to reintegrate patients into neighborhood self-help patterns where each would be a member of a network of friends who know and help each other. This is an attempt to adapt the positive elements of village type society to construct a social bond among the severely disabled who have dropped out of the normal patterns of social intercourse.

Has it worked? It is too early for a comprehensive evaluatinn. However, a small group of patients now meet in their own group outside of the Agency to play cards. Patients who can drive cars transport other patients to the Activity Program. Sympathy cards are sent to sick members. Members who do not show up are telephoned.

Do group activity programs preclude the need for individual counseling and casework? The answer is no. In our experience, the counseling help offered by the Demonstration Program Rehabilitation Counselor was instrumental in getting several patients to enter the Activities Program who otherwise would have lacked the motivation or courage to try. Other patients have problems too personal to voice even in group counseling sessions. Both individual counseling casework and group activity programs are necessary.

During the Fall of 1970 a team of three graduate social work students from the School of Social Welfare,,University of Wisconsin - Milwaukee were assigned for field work at the Curative Workshop. They were under the supervision of a UWM faculty member Field Instructor,who was also a member of the Stroke Policy Committee. In November, these students, under the supervision of their Field Instructor, set up a half-day-a-week activities program for neighborhood severely disabled people. This augmented the group social work field experience of the students. It was carried on in a church. Although the project was inspired by the discussions which had been going on in the Stroke Policy Committee meetings, this special project was carried on directly under the auspices of the University,not under the auspices of the Curative Workshop. The clients in this program were not necessarily Curative Workshop patients.

Attendance was averaging 18 by March, 1971 with a top attendance of 27. New members were recruited by old members. Two undergraduate social work students were also helping. Transportation was a big problem and was met by transporting patients in the private cars of the students and volunteers. However, some of the clients used buses and other forms of transportation.

The group became increasingly autonomous. Leaders emerged and the group did its own program planning as the students relaxed their leadership role. By the Spring of 1971, the group was planning its activities two weeks in advance. At the time of the preparation of this report,attendance ranged from 24 to 34. Further information about this special program, developed by graduate social work students,is available by writing the Research Department, Curative Workshop of Milwaukee.

Satellite Program vs. Central Agency Activity Program
Summary and Implications

Summary	Implications
The completion of the demonstration portion of the project stimulated the Project Policy Committee to take a broader perspective toward the problem of meeting the social needs of stroke patients.	Acting in an advisory capacity, a Project Policy Committee can act as a sounding board for different points of view and can motivate and encourage staff members and student interns to explore in new directions.
An Agency Activities program for severely disabled individuals started December, 1967. This developed to a total of 50 patients by June 1971.	This has great promise as a laboratory in developing new techniques in personal, educational and avocational activities development through group counseling, group and individual activities, educational programs and subcontract work.
Patients assumed responsibility for program planning, supervising other patients and departmental record keeping	Giving patients responsibility seems to be the key to developing individual initiative, motivation and self-confidence.
A spot map was developed showing the location of current severely disabled Curative Workshop patients who might benefit from satellite centers.	The spot map is a very useful managerial tool for program planning and other decision making.
A survey of possible facilities found 22 sites including 14 churches and 2 housing projects.	Churches have a great deal of available, little-used space which can be made available for socially useful purposes.
Six organizations with good facilities were interested.	Many churches are actively seeking ways to help in the community.
One church donated $100 to the Activities Program and pledged $1,000 for a satellite center.	An active liason is required to convert good intentions into going programs.
In November, 1970, 3 graduate social work students set up a half day- a-week activities program in a church. Average attendance was 18 by March, and increased to 24 to 34 in June.	The potential of graduate social work students for developing pilot programs is excellent. This was an unexpected payoff from an RSA Training Grant to the School of Social Work of the University of Wisconsin - Milwaukee.

CHAPTER 5

CONTROLLED STUDY OUTCOME

The purpose of this project was to determine whether providing stroke patients and their families with intensive rehabilitation counseling or casework services would result in maintaining, and possibly improving, patient gains after the completion of a rehabilitation program. The results were to be evaluated by comparing an experimental and a control group.

In other chapters we have discussed counseling inputs and records of counseling activity. In this Chapter we will discuss various measures of patient performance and attitude, intra-family relationships, social relationships outside of the family, avocational activity participation and knowledge of community resources.

This was not a research project but a demonstration project with an evaluation built in. In a demonstration project of this type, service is provided as the first consideration and research measurements are less rigorous because of this. Research needs must frequently give way to Agency service policies. Hence, a demonstration project of this type is a compromise between trying out a new service idea and trying to measure it. This makes both measurement and objectivety difficult.

To implement the evaluation of the project we tried to obtain as many different kinds of measurements between the experimental and control groups as possible. This chapter reports on the outcome of these measurements.

It was believed that greater use of household adaptations is desirable and this was used as an outcome measure as indicated in the following table. No significant difference was found between the experimental and control groups in the number of families making household adaptations ($\chi^2 = .85$, $p \sim .40$).

Table 46: Average Number of Household Adaptations Experimental vs. Control

	N = 43, Experimental Patients		N= 38, Control Patients		N= 81, All Patients	
No. families making	27	63%	20	53%	47	58%
No. adaptations made	59		47		106	
Average per family	2.18		2.35		2.25	

The success criterion of perhaps greatest interest is that of returning to work. Few patients returned to work. There was no significant difference between the groups in this respect. In addition, about three-fourths of all patients defined themselves as out of the labor market.

Table 47: Employment Status of Patients After a Stroke, Experimental vs. Control

	Experimental		Control		All Patients	
Returned to work	2	4%	4	10%	6	7%
Tried to find work but not successful	6	13%	3	8%	9	10%
Hope to return to work in future	3	6%	3	8%	6	7%
Not working, no plans to return	37	77%	30	75%	67	76%
Total	48	100%	40	101%	88	100%

It is believed that an agreement between the patient and spouse on what the patient is able to do in the way of activities of daily living is a positive sign of interspouse adjustment and likely a more realistic perception by both patient and spouse of the limitations imposed by the impairment. Table 48 following shows no significant difference between the two groups in rate of agreement of couples on the patient's ability to perform MADLI items.

Table 48: Agreement Between Patients and Spouses on Rating of Patients on MADLI, Experimental vs. Control

	N = 10, Experimental		N = 13, Control		N = 23, All Patients	
Number of agreements	72	92%	91	91%	163	92%
Number of comparisons	78		100		178	

It is believed that changes in performance of household tasks are desirable as a means of intrafamily adjustments to stroke-imposed limitations. In using this as a measure, we recognize that variables such as intensity or extensity of impairments, which may not be equal in both groups, may force these changes. In any event, experimental patients tended to average more changes.

Table 49: Average Number of Changes in Performance of Household Tasks, Experimental vs. Control

	Experimental			Control		
	N=21, Men	N=21, Women	N=42, All Experimental	N=24, Men	N=12, Women	N=36, All Control
Average No. changes	7.57	11.57	9.57 *	6.58	9.25	7.47 *

* t = 1.7, p≈.10 , Experimental patients tended to average more changes.

As Table 50 indicates, most of the patients stopped performing some household tasks. It was felt that patients who continued, even at a decreased level, to perform household tasks, were making a distinctly better adjustment than those who stopped entirely. More of the women in the experimental group continued to perform tasks at a decreased rate than did the women in the control group.

Table 50: Types of Changes in Patient Performance of Household Tasks, Experimental vs. Control

	Experimental			Control		
	N=21, Men	N=24, Women	N=45, All Experimental	N=21, Men	N=12, Women	N=33, All Control
Patient stopped performing task	126 89%	196 83%	322 85%	122 81%	97 90%	219 85%
Patient decreased performing task	4 3%	33* 14%	37 10%	10 7%	7* 6%	17 7%
Patient increased performing task	12 8%	6 3%	18 5%	18 12%	4 4%	22 9%
Total changes involving patient	142 100%	235 100%	377 100%	150 100%	108 100%	258 101%

* $X^2 = 4.11$, $p < .05$, Experimental women continued to perform tasks at a decreased rate more often than Control women.

The assumption was made that good adjustment is positively related to rate of interpersonal interaction. The next three tables present various measurements of this.

Table 51 following gives the most general measurement of people contact, the average number of people seen once a week or more. In this measurement, the women in the control group were found to have more contacts than women in the experimental group.

Table 51: Average Number of People Seen Once a Week or More by Patients, Experimental vs. Control

	Experimental			Control		
	N=23, Men	N=25, Women	N=48, All Experimental	N=26, Men	N=14, Women	N=40, All Control
Average number	3.00	1.88*	2.42	2.73	2.78*	2.75
Standard Deviation	1.32	1.03	1.30	1.89	1.16	1.67

* $t = 2.43$, $p < .05$, Control women had a higher average than Experimental women.

Perhaps more significant in terms of positive social relations is the measurement of the types of people seen once a week or more. Women in the experimental group saw a higher proportion of people outside the family than did women in the control group.

Table 52: Types of People Seen Once a Week or More by Patients, Experimental vs. Control

	Experimental			Control		
	N=23, Men	N=25, Women	N=48, All Experimental	N=26, Men	N=14, Women	N=40, All Control
Family/ Relatives	55 80%	33* 70%	88 76%	58 82%	34* 87%	92 84%
Friends/ Neighbors	14 20%	14* 30%	28 24%	13 18%	5* 13%	18 16%
Total People seen	69 100%	47 100%	116 100%	71 100%	39 100%	110 100%

* $\chi^2 = 3.56$, $p<.10$, Experimental women tended to see a higher proportion of non-family people than did Control women.

A final supposition was made that stroke patients might help sustain each other by maintaining social contacts. Therefore, a higher rate of contact between patients was desirable. No difference was found between the two groups in the amount of contact with other stroke patients.

Table 53: Contact with Other Stroke Patients, Experimental vs. Control

	Experimental	Control	All Patients
Once a month or more	11 23%	9 22%	20 23%
Less than once a month	37 77%	31 78%	68 77%
Total	48 100%	40 100%	88 100%

An obvious criterion for successful post stroke adjustment is the degree of participation in avocational activities. This was measured in three different ways in Tables 54, 55, and 56, following.

The first measurement was the average number of avocational activities reported before the stroke occured and at the time of the followup interview. Patients in the control group exceeded the patients in the experimental group in the number of activities both before and after.

Table 54: Average Number of Avocational Activities, Experimental vs. Control

	Experimental			Control		
	N=23, Men	N=22, Women	N=45, All Experimental	N=25, Men	N=14, Women	N=39, All Control
Before stroke	5.09	4.64	4.87*	6.00	5.71	5.90*
At followup	2.91***	2.95	2.93**	4.36***	4.43	4.38**
% decrease	43%	36%	40%	27%	22%	26%

* t = 1.63, p≈ .10, Control patients tended to have more pre-stroke activities.
**t = 2.50, p< .05, Control patients did have more activities at followup.
***t= 2.35, p< .05, Control men had more activities at followup.

Next measured was whether patients increased or decreased their avocational activities after the stroke, or stopped them entirely. Again, control patients seemed to be more active.

Table 55: Changes in Patients' Frequency of Participation in Avocational Activities after Stroke, Experimental vs. Control

	Experimental			Control		
	N=23, Men	N=22, Women	N=45, All Experimental	N=25, Men	N=14, Women	N=39, All Control
Patient stopped activity	53 45%	50 49%	103* 47%	50 33%	28 35%	78* 34%
Patient does less	16 14%	13 13%	29 13%	24 16%	6 8%	30 13%
Patient does same	22 19%	22 22%	44** 20%	51 34%	28 35%	79** 34%
Patient does more	26 22%	17 17%	43 20%	25 17%	18 22%	43 19%
Total pre-stroke activities	117 100%	102 101%	219 100%	150 100%	80 100%	230 100%

*χ^2 = 8.03, p<.01, Control patients stopped fewer activities than Experimental patients.

**χ^2= 5.22, p<.05, Control patients continued at the same rate in more activities than Experimental patients.

Finally, a comparison was made between the two groups with respect to how often patients started new avocational activities after the stroke. No differences were found.

Table 56: Frequency of Patients Starting New Avocational Activities After a Stroke, Experimental vs. Control

	Experimental			Control		
	N=23, Men	N=22, Women	N=45, All Experimental	N=25, Men	N=14, Women	N=39, All Control
Patient started new activity	3 4%	13 20%	16 12%	9 9%	10 16%	19 12%
Total Activities at Followup	67	65	132	100	62	162

As part of the plan to encourage greater independence of the patients and their families, the counselor made an effort to acquaint the families with some of the services and programs available in the greater Milwaukee area. For example, on several occasions, she took a small group of patients out to one of the Senior Citizen Centers in the hope that this would encourage them to continue on their own. She also notified all her clients at tax time of their potential eligibility for the Wisconsin Homestead Tax Credit. The entire project staff worked closely with a local War on Poverty Program called Project Involve in their attempt to compile a "Handbook of Community Services" available to the elderly in Milwaukee. The result was that there was a tendency for the experimental patients to be more knowledgeable about the community services than the control patients. This difference usually was not significant, but the direction was in favor of the experimental group. More Experimental then Control patients knew about 12 of the 16 services. In nine cases X^2 tended toward significance ($p < .30$). While the number of patients actually using the services was too small to permit any statistical test of difference, the experimental patients more frequently used 10 of the 16 services.

Table 57: Families' Knowledge of Milwaukee County Community Resources, Experimental vs. Control

	N=36, Experimental		N=30, Control		χ^2	p
Visiting Nurse Association	30	83%	24	80%	-	-
Washington Park Senior Center	28	78%	20	67%	1.02	.30
Local Senior Citizens' Center	25	69%	23	77%	-	-
Federal Food Stamp Program	22	61%	19	63%	-	-
Bookmobile	22	61%	14	47%	1.38	.25
Golden Age Clubs	19	53%	16	53%	-	-
Marquette University Dental Clinic	23	64%	12	40%	3.75	.05
Tuberculosis Clinic	22	61%	12	40%	2.92	.10
Union Drug Stores	20	56%	13	43%	-	-
Immunization Clinic	18	50%	10	33%	1.86	.20
Talking books	15	42%	12	40%	-	-
Wisconsin Homestead Tax Credit	13	36%	12	40%	-	-
Project Involve	13	36%	6	20%	2.07	.15
Mail Order Drug Services	14	39%	4	13%	5.39	.02
Multiphasic Physical Exam	12	33%	5	17%	2.38	.15
Project Involve Telephone Service	10	28%	4	13%	2.04	.15

The final comparison made was of the extent to which patients and their spouses agreed in describing their attitudes and perceptions of the stroke situation. This was done by means of standardized attitude inventories. It was felt that agreement should indicate better adjustment. No significant differences were found.

Table 58: Average Agreement Between Patients and Spouses on 22 Patient Description Items, Experimental vs. Control

	N=13, Experimental		N=13, Control		N=26, All Patients	
Average No. of items upon which couples agreed	15.23	69%	16.85	77%	16.04	73%
Average No. of items upon which couples disagreed	6.77	31%	5.15	23%	5.96	27%
Total of items (t = .99, NS)	22.00	100%	22.00	100%	22.00	100%

Recapitulating, we see that the experimental group exceeded the control group to a significant degree in the following positive factors:

Higher average number of changes in performance of household tasks
More knew about 12 out of 16 community resources
More used 10 out of 16 services

Women in the experimental group exceeded the women in the control group to a significant degree in these positive factors:

Continuing, even at a decreased level, to perform household tasks
Seeing a higher proportion of people outside the family once a week or more

Patients in the control group exceeded those in the experimental group to a significant degree in these positive factors:

Higher average number of avocational activities both before the stroke and at the time of the followup interview
Stopped fewer avocational activities after the stroke
Continued the same rate of participation in more avocational activities after the stroke

Men in the control group exceeded the men in the experimental group to a significant degree in this positive factor:

Average number of avocational activities at the time of the followup interview

Women in the control group exceeded the women in the experimental group to a significant degree in this positive factor:

Higher average number of people seen once a week or more

As measured by these indicators there is no clear cut evidence that counseling improved the adjustment of stroke patients and their spouses.

The one area of improvement which seems linked to counselor input is with respect to community resources. Here we know the counselors made a special effort to inform the patients in the experimental group of services available. The followup interview found that experimental patients both more often knew of and used community resources. From this it may be inferred that this is a fruitful area of counselor activity.

Failure to find more evidence of counselor effectiveness may be attributed to a variety of causes including the following:

1. Counseling does not help.
2. The particular counselors in this Project were not effective.
3. The ways of measuring their effectiveness were inadequate.
4. The experimental group was more impaired or inflexible than the control group.

Having exhausted the objective data we turn to our personal impressions. In repeated studies, counselors and psychotherapists have had difficulty in demonstrating success, suggesting that this is an elusive field for adequate measurement.

We believe that because of the empathy our counselors showed, there was a mutual attraction between our counselors and the families with the most difficulties. Thus the bulk of counselor time was devoted to the 21 most difficult cases rather than being spread equally over the total case load. Such measures of success, as we were able to devise, better measured average gains of all patients rather than the salvaging of a few families from crisis situations.

That these families in crisis were continually telephoning the counselors for help verifies that the families themselves saw an acute need for counseling and casework help. It is not possible to determine whether help would have been obtained elsewhere in the community if we had not provided it.

Controlled Study Outcome: Summary and Implications

Summary

On 15 measurements of post stroke adjustment the experimental group exceeded the control on 5; the control group exceeded the experimental group on 4. In 6 there were no differences.

Measurement Categories	N of Measures
Use of household adaptations	1
Employment status	1
Patient-spouse MADLI rating agreement	1
Household task performance	2
Social interactions	3
Avocational Activities participation	4
Knowledge of community resources	1
Use of community resources	1
Patient-spouse attitude agreement	1

Implications

There is no clear cut evidence that counseling improved the adjustment of these stroke patients and their families.

The bulk of counselor time was devoted to crisis intervention in 21 of the most difficult cases. Success measures better measured average gains of all patients rather than crisis reduction in a few families.

Input-output Linkage

Counselors made special effort to inform experimental patients of community resources available. Success in this was reflected in that the experimental group both had greater knowledge of and made greater use of community resources.

Systematically informing patients of available community resources is a fruitful area of counselor activity.

CHAPTER 6

FOLLOWUP FINDINGS

A comprehensive detailed followup by structured interview was undertaken for several reasons. The primary purpose was to measure differences in the overall adjustment of the experimental vs. the control group in order to test the demonstration that the adjustment of patients and their families will be improved by intensive counseling/ casework. The second purpose was to describe, by counting and summarizing numerically the occurrence of relevant behavior and attitudes in a group of patients rather than portraying this through the case history approach, how stroke families live and cope. The third purpose was to gain, through a four year period, a longitudinal view of changes which take place among stroke families.

The followup consisted of as many patients and their spouses as could be located in both the experimental and control groups. The followup interview was held between 11 and 37 months after the patient was admitted to the rehabilitation program at the CVA Clinic. The average time since admission was 22 months. Eighty-eight (67%) of the original project population were interviewed. Nineteen (14%) of the 132 patients had died. This is an average annual mortality rate of 3.5% or 35 per thousand. Seventeen patients (13%) had moved and could not be located and eight (6%) refused to cooperate.

Table 59: Followup Interviews Completed

	Experimental		Control		All Patients	
Interview completed	48	73%	40	61%	88	67%
Patient deceased	9	14%	10	15%	19	14%
Patient moved	5	8%	12	18%	17	13%
Patient refused	4	6%	4	6%	8	6%
Total	66	101%	66	100%	132	100%

Most of the interviews were conducted by a male, recent college graduate, research assistant. In about half of the interviews the spouse was present as well as the patient. This was more frequently the case when a woman was the patient. The followup interview schedule was developed from the results of twenty-five preliminary unstructured interviews, completed during the summer of 1969 and previous studies of families and the disabled done by Artes (1967 - stroke), Blood and Wolfe (1960 - family), Christopherson (1963 - family), and Roen (1968 - general). * Since not all patients answered every question, in the tables that follow the number of patients responding is shown.

* A copy of this thirteen-page structured interview schedule may be obtained by writing: Research Department, Curative Workshop of Milwaukee, 750 North 18th Street, Milwaukee, Wisc. 53233.

A. Housing

There was no appreciable difference between the experimental and control groups in terms of residence and living situation either before or after the stroke. The vast majority of patients (83%) lived in a private home or flat. Most (70%) were with their spouse, and the same proportion were with dependent children (20%) as with independent children (28%). There was very little change in either living situation or type of dwelling as a result of the stroke. As might be expected, fewer people lived alone, or with the spouse only, after the stroke, but even these decreases are slight. Less than 10% of the cases ended up in a nursing home although this was an eight-fold increase over the pre-stroke percentage of patients in homes. This percentage might have been slightly higher had we been able to contact all the former patients.

Table 60: Residence of Patients at Followup

Type of Residence	Before Stroke		At Followup	
House	90	68%	67	68%
Flat	23	17%	15	15%
Apartment	15	11%	9	9%
Trailer	3	2%	-	-
Nursing Home	1	1%	8	8%
Total	132	99%	99	100%

Table 61: Living Situation of Patients at Followup

Type of Situation	Before Stroke		At Followup	
With spouse only	49	37%	31	31%
With spouse and children over 18	23	17%	20	20%
With spouse and children under 18	24	18%	18	18%
With children over 18	9	7%	8	8%
Nursing Home	1	1%	8	8%
Alone	16	12%	6	6%
With relatives	8	6%	5	5%
With children under 18	1	1%	2	2%
With spouse and relatives	1	1%	1	1%
Total	132	100%	99	99%

There was no difference in the number or the type of adaptations made by experimental and control clients, or by men and women clients. About 70% of all cases interviewed had made some household changes. About a third of the total changes were simple rearrangement of furniture, or removal of rugs, which involved no expense or equipment. Only 15% of the adaptations mentioned were suggested by medical or paramedical professionals. These were usually grab bars or kitchen devices.

Table 62: Household or Building Adaptations for Patients

Type of Adaptation	No. of Cases in Which Adaptations Were Made	
Removed throw rugs, small carpets	22	28%
Grab bars in bathroom	16	20%
Railings on stairways, along wall	12	15%
Stool, rubber mat for bathtub	11	14%
Special furniture: beds, chairs etc.	9	11%
Commode, raised seat for toilet	8	10%
Ramps for stairways, split level, car	6	8%
One-handed kitchen devices	6	8%
Additional telephone jacks	5	6%
Rearrangement of furniture	4	5%
Not waxing linoleum	2	3%
Removed door or threshhold	2	3%
Steering knob for car	1	1%
Weaving loom	1	1%
Pulley in bedroom	1	1%
Total number of adaptations	106	Range 0 to 8
Mean for all clients completing question	1.33	N = 80
Mean for those clients making adaptations	1.93	N = 55

B. Financial Status

Not surprisingly, both the income and savings level dropped somewhat after a stroke. The drop was most severe when it was a younger working male who suffered the stroke. For the families where the husband had already retired, the adjustment was less difficult. At the time of the followup a little more than half the families involved were living on an income less than $4,000 yearly and had less than $1,000 in savings against a future emergency.

Table 63: Financial Situation of Patients

	Income				Savings			
	under 4,000	4,000 to 7,000	7,000 to 10,000	over 10,000	under 1,000	1,000 to 3,000	3,000 to 6,000	over 6,000
Before stroke	20 33%	8 13%	15 25%	17 28%	16 30%	17 32%	14 26%	6 11%
At Followup	33 55%	15 25%	12 20%	- -	27 51%	12 23%	8 15%	6 11%
Families completing question: 60					Families completing question: 53			

Before the stroke about 2/3 derived their income from wages and salaries and only 1/3 were on social security. After the stroke the figures reversed, now 72% receive social security and only 30% still rely on wages and salaries. Few clients were, or are, on public assistance.

Table 64: Sources of Income for Patients

Before Stroke			At Followup		
Wages, salaries	53	70%	Social Security	55	72%
Social Security	24	32%	Company retirement	28	37%
Company retirement	12	16%	Wages, salaries	23	30%
Rent	12	16%	Rent	15	20%
Interest, dividends	5	7%	Disability comp. or unemployment	10	13%
Veterans benefits	4	5%	Public assistance	7	9%
Public assistance	3	4%	Veterans benefits	6	8%
Children	2	3%	Interest, dividends	6	8%
Disability comp. or unemployment	1	1%	Children	4	5%
Families completing question: 76			Families completing question: 76		

A majority of the patients were forced to use at least part of their savings because of the stroke. A third or more reported cutting back their expenses for socializing, recreation, clothing and food. Less than 10% of the families reported that they were forced to more drastic steps such as selling property, falling behind in payments, borrowing money or going without necessities. All but one family had some form of health insurance and almost all of those eligible had availed themselves of medicare assistance.

Table 65: Adjustment to Decreased Income

Used savings (or part of it)	40	53%
Reduced social spending (eating out, nite clubbing, etc.)	33	44%
Reduced clothing spending	33	44%
Reduced recreation spending	32	43%
Reduced food spending	24	32%
Changed residence or living situation	7	9%
Cashed in stocks, bonds or insurance	7	9%
Borrowed money	7	9%
Fell behind in payments (rent, utilities, mortgage)	7	9%
Went without medical devices (medicine, drugs, etc.)	7	9%
Rented or leased property	5	7%
Contributions from children	5	7%
Sold property	1	1%

Families completing question: 75

C. Employment Status

Before the stroke about 2/3 of the male, and 1/3 of the female clients were working full time. By followup only 4% of the male and none of the female stroke victims had returned to full time work. Another 5% of each had returned to part-time status. There were a few cases where the spouses of a male client began to work or tried to find work after her husband's stroke but overall the percentage of spouses working actually decreased slightly over the course of the project. Since the stroke 7 or 14% of the male clients and 2 or 5% of the females have attempted to find employment, usually from their former employer. Another 12% of the men and 5% of the women cases said they still planned to return to work eventually.

Table 66: Employment Status of Men Patients and Spouses at Followup

	Men Patients				Spouses of Men Patients			
	Before Stroke		At Followup		Before Stroke		At Followup	
Full-time	48	64%	2	4%	12	20%	7	17%
Part-time	2	3%	2	4%	5	8%	4	10%
Not working	25	33%	45	92%	44	72%	31	74%
Total	75	100%	49	100%	61	100%	42	101%

Table 67: Employment Status of Women Patients and Spouses at Followup

	Women Patients				Husbands of Women Patients			
	Before Stroke		At Followup		Before Stroke		At Followup	
Full-time	16	29%	-	-	21	64%	10	45%
Part-time	4	7%	2	5%	1	3%	2	9%
Not working	35	64%	37	95%	11	33%	10	45%
Total	55	100%	39	100%	33	100%	22	99%

D. Performance in Activities of Daily Living

In Chapter 2 we reported on the patients' performance at admission and discharge on the Milwaukee Activities of Daily Living Inventory (MADLI). This Inventory is described in detail in Volume II, pages 7-14. Some patient performance ratings on the MADLI were subsequently secured at the time of followup and these findings are reported in the next three tables.

A total of 48 patients rated themselves on the MADLI. Not all cases had reason to rate themselves on every item however. At least three quarters of the patients saw themselves as independent on each item. Use of the dial phone was the highest with 93%, and ability to climb or descend stairs was the lowest with 73%. The men and women seemed to be about equal in terms of their own perception of their ability.

Table 68: MADLI Evaluation: Independent Ratings by Patients at Followup * (In Rank Order)

Activity	Men Patients		Women Patients		All Patients	
Dial phone	20	91%	22	96%	42	93%
Push button phone	10	83%	7	88%	17	85%
Leg braces	8	80%	10	91%	18	85%
Walking	18	82%	19	83%	37	82%
Transferring	15	75%	20	87%	35	81%
Wheelchair	9	90%	5	63%	14	78%
Eating	18	78%	19	79%	37	78%
Dressing	17	74%	18	75%	35	74%
Stairs	17	74%	18	72%	35	73%
Total number of independent ratings	132	80%	138	82%	270	81%

* Percentages are based upon the number of patients actually rating themselves on that activity. All patients did not rate themselves on all activities.

Forty-one spouses rated the ability of the husband or wife stroke patient to perform on the MADLI items. When the woman was a patient it was more difficult to get the spouse to fill out the rating form, he was often times at work. If the spouse of a woman patient was at home it usually meant that either the wife was too disabled to be left alone, or that the couple was older and the man had retired. Either situation might account for the much lower ratings given by the spouses to the women patients. They averaged 17% fewer independent ratings per activity. While the rank order of activities was pretty much the same as that obtained when the patients ranked themselves, the relative frequency of independent ratings was less when the spouse did the

judging. Compared to their own ratings men patients averaged 8% fewer independent ratings and women patients 26% fewer, when the spouse did the rating.

Table 69: MADLI Evaluations: Independent Ratings by Spouses at Followup* (In Rank Order)

Activity	Spouses of Men Patients		Spouses of Women Patients		Spouses of All Patients	
Dial phone	22	81%	9	64%	31	76%
Push button phone	8	80%	5	71%	13	76%
Eating	22	81%	9	64%	31	76%
Wheelchair	10	83%	3	43%	13	68%
Walking	20	74%	7	50%	27	66%
Transferring	17	71%	6	50%	23	64%
Stairs	17	65%	7	50%	24	60%
Dressing	17	63%	7	50%	24	58%
Leg braces	8	53%	5	55%	13	54%
Total number of independent ratings	141	72%	58	55%	199	66%

*Percentages are based upon the number of spouses actually rating the patient on that activity. Not all spouses rated the patient on all activities.

There were twenty-three couples where both the patient and the spouse evaluated the patients ability to perform the activities. When those ratings are compared, they reveal a remarkable agreement between husband and wives. Transferring and walking had the lowest rates of agreement (83% and 87% respectively) but both these figures are above the highest rates of agreement between patient and spouse on admission to the Agency (83% on dial phone). At admission the couples (not necessarily the same couples) agreed only 70% of the time. At followup there was 91% agreement. When there was a disagreement, the patient usually gave himself the higher rating (87% of the time at followup, 63% at admission).

Table 70: Agreement Between Patient and Spouse Ratings on MADLI at Followup* (In Rank Order)

Activity	Men Patients		Women Patients		All Patients	
Eating	15	94%	7	100%	22	96%
Stairs	15	94%	7	100%	22	96%
Push button phone	9	100%	4	80%	13	93%
Dial phone	15	94%	6	86%	21	91%
Dressing	14	87%	7	100%	21	91%
Walking	15	94%	5	71%	20	87%
Leg braces	9	90%	4	80%	13	87%
Wheelchair	8	89%	4	80%	12	86%
Transferring	13	81%	6	86%	19	83%
Total number of agreements	113	91%	50	92%	163	91%

* Percentages are based upon only the number of comparisons actually made on each activity. Not all couples compared every item.

E. Performance of Household Tasks

A comprehensive list of 21 household activities was developed, which included such affective type duties as family correspondence and socializing, as well as the purely instrumental type chores like dusting and cleaning. The list incorporated many of the activities included in previous studies by Ballweg (1967 - family), Blood and Wolfe (1960 - family), and Christopherson (1960 - family). Table71 below shows that, as the previous studies had demonstrated, most of the activities tend to be divided along sex lines, the wife having primary responsibility for the housework, and family affairs in general. Only two of the 21 items seemed to be the primary concern of the husbands - yardwork and minor repairs - and these are both traditionally masculine areas of interest. Nine tasks were almost universally performed by the wives, and these were all traditionally feminine jobs: ironing, sewing, dusting, etc. Of the remaining ten, only one -trash removal - saw the husband with an edge in responsibility. Shopping and day-to-day decisions were done by the wife herself half the time, and shared with the husband the other half. Family finances, furniture moving and window washing were a concern of the husband in a third of the families, the wife in another third and of both in the remaining third.

The conclusion **that** emerges from these figures is that specific tasks were almost always done by one spouse or the other, while the more general decision making areas of planning, recreation and socializing were considered as joint projects.

Table 71: Performance of Household Tasks Before Stroke*

Tasks	Husband	Wife	Both	Child	Other
Ironing	3%	88%	3%	4%	3%
Mending, sewing	1%	88%	3%	5%	4%
Bed making	5%	84%	4%	4%	3%
Dusting	5%	82%	6%	6%	1%
Meal Preparation	4%	80%	11%	4%	1%
Laundry	3%	79%	10%	4%	5%
Cleaning(vacuuming, etc)	9%	77%	10%	4%	4%
Dishwashing	7%	70%	16%	5%	1%
Family Correspondence	12%	72%	10%	4%	1%
Food Shopping	12%	46%	36%	6%	4%
Other Shopping	6%	42%	44%	7%	1%
Long Range Planning	6%	24%	62%	5%	-
Family Recreation	4%	31%	58%	6%	-
Family Socializing	4%	36%	53%	6%	-
Day-to-day Decisions	5%	36%	42%	4%	-
Family Finances	32%	38%	21%	5%	1%
Moving Furniture	25%	32%	35%	7%	4%
Washing Windows	27%	41%	21%	6%	4%
Trash, Garbage Removal	42%	32%	15%	6%	1%
Yardwork	54%	16%	16%	9%	7%
Minor Repairs	67%	11%	7%	6%	14%

Clients completing question: 81

* Not all clients answered each item and some items allowed for more than one response, i.e. the wife and a child may perform a task. These percentages do not always total 100%.

Table 72 shows the different types of changes that the families underwent after the stroke made the original division of family labor impractical. When a man was the patient it was relatively simple: what he stopped doing, his wife started to do. When a woman was the patient it was a little more intricate. Probably because many of a woman's roles are more sex specialized than a man's (sewing, ironing, etc.), the husbands of woman patients were not able to take over all of their wife's duties. Usually a daughter was called on to help. Also the husbands would often continue to work and not be at home to do the housework. While neither men nor women patients were noticeably eager to start doing new activities, the men did so somewhat more frequently than the women (.67 to .30 per patient). However, the women were slightly more willing to share responsibility for a job they had previously done themselves (1.21 to .31 per patient). There did not seem to be any pattern to what activities the men patients started if they started any, or the women patients shared, if they shared any.

Table 72: Average Number per Family of Each Type of Change in Performance of Household Activities (in Rank Order)

Type of Change	Men patients (N=45)		Women patients (N=33)	
Patient stopped performing activity	5.71	85%	8.88	85%
Spouse increased performing activity	4.69	67%	5.15	48%
Child increased performing activity	1.96	28%	4.12	38%
Other increased performing activity	.40	6%	1.85	17%
Patient decreased performing activity	.31	5%	1.21	12%
Patient increased performing activity	.67	9%	.30	3%
Total average changes per family	7.04	100%	10.73	100%

Table 73 then shows the effect of a stroke on the performance of those same 21 household tasks. As might be expected, the effect was greater when the wife was the patient. A third or more of the families with women patients had to make some adjustment for each of the 21 activities. There were only eight activities for which more than a third of the families with men patients were affected. On the average, a stroke to a women resulted in 11 changes in the performance of the household duties, while when a man was the patient, only 7 activities were affected. This difference proved significant ($t=2.95$, $p<.01$).

Table 73: Household Activities Requiring Changes in Performance After a Stroke (In Rank Order)

Men Patients (N = 45)			Women Patients (N = 33)		
Activity	Families Changing		Activity	Families Changing	
Yardwork	36	80%	Mending, sewing	23	70%
Minor repairs	32	71%	Food shopping	23	70%
Moving furniture	27	60%	Moving furniture	23	70%
Washing windows	24	53%	Washing windows	22	67%
Food shopping	24	53%	Other shopping	22	67%
Trash, garbage removal	21	47%	Meal preparation	21	64%
Other shopping	20	44%	Ironing	19	58%
Family finances	20	44%	Dishwashing	18	55%
Meal preparation	13	29%	Cleaning	18	55%
Dishwashing	13	29%	Laundry	18	55%
Cleaning	12	27%	Yardwork	18	55%
Family socializing	10	22%	Bed making	15	45%
Family recreation	10	22%	Family correspondence	15	45%
Daily decisions	10	22%	Family finances	13	39%
Long range planning	10	22%	Daily decisions	13	39%
Dusting	8	18%	Long range planning	13	39%
Bed making	7	16%	Minor repairs	13	39%
Laundry	7	16%	Dusting	13	39%
Ironing	5	11%	Trash, garbage removal	12	36%
Family correspondence	5	11%	Family socializing	11	33%
Mending, sewing	3	7%	Family recreation	11	33%
Total no. of changes	317		Total no. of changes	354	
Average per family	7.04*		Average per family	10.73*	

*t = 2.95, $p < .01$; families with women patients required more changes than families with men patients.

F. Patterns of Help

Who helped the patient varied according to whether the patient was a man or a woman. The following table shows the distribution of help according to the helper. This excludes the help given by spouses. The burden fell most heavily on one person. When a man was the patient, 31% of the time the help was given by one son, and 31% of the time by one daughter. This accounted for three-fifths of the help. When a woman was the patient, 43% of the time help was given by one daughter. Next in line, help was given by one sister in 14% of the cases. Help given by one son amounted to only 12%.

Help given by someone outside of the family (neighbor, friend or co-worker) amounts to only 11% for men patients; 16% for women patients.

Neighbors account for only 7% of the help given to men and 8% of the help given to women.

Table 74 : Who Helped the Patient? (In Rank Order)

When the Patient was a Man			When the Patient was a Woman		
Helper			Helper		
One son	62	31%	One daughter	66	43%
One daughter	62	31%	One sister	21	14%
Two daughters	18	9%	One son	18	12%
One sister	14	7%	Neighbor	12	8%
Neighbor	13	7%	Friend	11	7%
Friend	6	3%	Parents	8	5%
One brother	5	3%	Two daughters	5	3%
Two sons	4	2%	Two sons	4	3%
Parents	4	2%	One brother	3	2%
Three or more daughters	3	2%	Two sisters	2	1%
Cousins	3	2%	Two brothers	2	1%
Two sisters	2	1%	Co-worker	1	1%
Co-worker	1	1%	Neice/nephew	1	1%
Total	197	101%	Total	154	101%

The forms of help given also varied according to the sex of the patient. The following table shows the distribution of the forms of help given, both when the patient was a man and when the patient was a woman. Transportation topped the list for men patients accounting for 25% of the help given. This is greater for men than for women. Transportation of some men to work may account for this.

Patient care tops the list of help given women patients. Shopping help ranks second for both men and women patients.

The percentage of help devoted to shopping, patient care, chores, advice, and child care is about the same for men and women.

Men patients receive more help in maintainance and transportation. Women patients receive more financial help and help with living accommodations, and supplies.

Table 75: What Forms of Help Were Given to the Patient (In Rank Order)

When the Patient was a Man			When the Patient was a Woman		
Type of Help			Type of Help		
Transportation	49	25%	Patient care	25	16%
Shopping	35	18%	Shopping	24	16%
Patient care	27	14%	Transportation	24	16%
Chores	26	13%	Chores	20	13%
Maintainance	23	12%	Financial	16	10%
Financial	13	7%	Living accommodations	13	8%
Advice	11	6%	Advice	12	8%
Supplies	7	4%	Supplies	11	7%
Living accommodations	5	3%	Maintainance	7	5%
Care of children	1	1%	Care of children	1	1%
			Other	1	1%
Total	197	103%	Total	154	101%

Patterns of help were reciprocal. Whom the patients helped rather closely followed the pattern of who helped them. Thus when a man was the patient, one daughter was given 39% of the help and one son 32% for a total of 71% of the help given. For women patients the pattern shifted to help to one daughter 56% of the time and one son 18% for a total of 74% of the help given.

Help given neighbors closely approximated the amount of help received from them. Thus men patients gave 8% of their help to neighbors and received 7% from them. Women patients gave 6% of their help to neighbors and received 8% from them.

This says nothing about either the quality or amount of help given. It merely indicates the distribution of help coming from and going to different categories of significant others.

Table 76: Whom the Patient Helped (In Rank Order)

When the Patient was a Man			When the Patient was a Woman		
Person Helped			Person Helped		
One daughter	24	39%	Daughter	19	56%
One son	20	32%	One son	6	18%
Neighbor	5	8%	Two sons	3	9%
Two or more daughters	4	6%	Brother	2	6%
Two sons	4	6%	Neighbor	2	6%
Sister	2	3%	Friend	2	6%
Parents	2	3%			
Cousins	1	2%			
Total	62	99%	Total	34	101%

How patients helped others is shown in the following table. Surprisingly, men patients took care of children more frequently than women patients. Rather naturally they also helped out financially and in furnishing living accommodations more frequently than did women.

Women patients helped considerably more with chores, advice and transportation. Men patients helped slightly more on shopping, and maintainance.

Again this was a measure of the distribution pattern of help given by patients, not of the quantity or quality of it.

Table 77: How the Patient Helped (In Rank Order)

When the Patient was a Man			When the Patient was a Woman		
Type of Help			Type of Help		
Care of children	17	27%	Chores	9	26%
Living accommodations	16	26%	Living accommodations	6	18%
Finances	7	11%	Care of children	5	15%
Shopping	6	10%	Advice	5	15%
Chores	5	8%	Transportation	3	9%
Maintenance	4	6%	Financial	2	6%
Advice	3	5%	Supplies	2	6%
Supplies	2	3%	Maintenance	1	3%
Transportation	2	3%	Shopping	1	3%
Total	62	99%	Total	34	101%

G. Social Contacts

Tables 78 and 79 below show the number and the types of people that patients see once a week or more. Men averaged significantly more contacts a week than women ($t=2.20$, $p<.05$) but even they averaged only 2.86 people seen a week. The women's mean was 2.20. Even more importantly, though, is the type of people seen. For both men and women about 80% of the people seen were family members. Sixty-five percent of those seen were a spouse or child. Clearly the patients were not interacting very often with their community.

Table 78 : Number of People Seen Once a Week or More by Patients (includes spouse)

	Men patients		Women patients		All patients	
0 persons seen	2	4%	1	3%	3	3%
1 person seen	10	20%	12	31%	22	25%
2 persons seen	10	20%	11	28%	21	24%
3 persons seen	12	25%	9	23%	21	24%
4 persons seen	5	10%	5	13%	10	11%
5 persons seen	7	14%	1	3%	8	9%
6 persons seen	2	4%	0	-	2	2%
7 persons seen	1	2%	0	-	1	1%
Total patients	49	99%	39	101%	88	99%
Total persons seen	140		86		226	
Average per patient	2.86*		2.20*		2.57	

* $t=2.20$, $p<.05$, Men see more people than women

Table 79: Types of People Seen Once a Week or More by Patients

	Men patients		Women patients		All Patients	
Spouse	40	29%	20	23%	60	26%
Daughter	32	23%	26	30%	58	26%
Son	19	14%	10	12%	29	13%
Friend	13	9%	10	12%	23	10%
Neighbor	12	9%	9	10%	21	9%
Sister	7	5%	6	7%	13	6%
Brother	7	5%	2	2%	9	4%
Parent	6	4%	3	3%	9	4%
Other relative	2	1%	0	-	2	1%
Co-worker	2	1%	0	-	2	1%
Total people seen	140	100%	86	99%	226	100%
Average per patient	2.86		2.20		2.57	

Of the 12 patients who were seeing fellow stroke victims at least once a week, seven were still receiving therapy at the Agency and the other five were in nursing homes. In reality only about 10% of the clients maintain any close relationship with other stroke patients once they leave the Agency. This would seem to highlight the need for programs t ase the client's transition from the status of a dependent patient to that of peer in social relationships. There were 20 clients (23%) who report having contact with other stroke patients in their house or someone else's home but the frequency of such social contact was very low. Patients did not seem to carry their relationship with fellow clients out of the physical setting of the Agency. Also, there was only one reported case of clients exchanging services with one another, in this case transportation.

Table 80: Frequency of Contact with Other Stroke Victims

At least once a week	12	14%
1-3 times monthly	8	9%
Less than monthly	5	6%

H. Avocational Activities

The following two tables describe the type and number of activities participated in by the patients. Table 82 indicates the relative popularity of the most frequently mentioned activities. It can be seen that the rank order was about the same for both men and women patients, and for the two time periods covered. Television watching, card playing and reading were the most often mentioned and the percentage of people doing each stayed fairly constant across sex and time lines. Hunting and fishing for the men, and knitting and sewing for the women, suffered large decreases between the stroke and followup.

Table 81 shows the average number of activities per patient for each type of patient, and at the different time periods. The control group patients had a higher rate of activity both before the stroke and at followup. However, the relative difference between men and women was the same for both groups. Before the stroke the men averaged about half an activity more than the women. At followup the men's and women's averages were almost exactly equal. If the women had fewer activities to begin with, they evidently stopped fewer after the stroke.

As with the performance of household activities (Table 50), it was unusual for a patient to continue an activity at a reduced rate. They usually either stopped completely (40% of pre-stroke activities) or continued at the same or even increased level (46% of pre-stroke activities). Only about 13% of the pre-stroke activities of the patients were continued at a reduced rate. The patients were also reluctant to begin new activities; only 12% of the activities being performed by the followup patients had been started since the stroke. Women patients seemed a little more willing to do this than the men; 18% of their present activities had been started since the stroke compared to only 7% of the men's activities.

Table 81: Average Number of Avocational Activities per Patient

	(N = 45) Experimental			(N = 39) Control		
	(N=23) Men	(N=22) Women	All ex. patients	(N=25) Men	(N=14) Women	All con. patients
Before stroke	5.09	4.64	4.87*	6.00	5.71	5.90*
At followup	2.91	2.95	2.93**	4.36	4.43	4.38**
% decrease	43%	36%	40%	27%	22%	26%

*t = 1.63, p = .10 Control patients tended to average more activities before the stroke.

**t = 2.50, p = .02 Control patients did average more activities at followup.

Table 82 : Avocational Activities Most Frequently Mentioned by Patients (in Rank Order)*

(N = 48) Men patients			(N = 36) Women patients		
	Activity	Before stroke	At Followup	Activity	Before stroke	At Followup
61	TV Watching	94%	92%	61 TV Watching	67%	86%
06	Card games	56%	44%	06 Card games	53%	31%
63	Reading	50%	42%	63 Reading	53%	56%
24	Fishing	42%	21%	60 Radio listening	42%	39%
60	Radio listening	29%	29%	41 Cooking	28%	19%
89	Union, employee organizations	27%	2%	67 Religious	25%	17%
25	Hunting	21%	4%	62 Movie going	22%	19%
66	Travel	21%	19%	46 Sewing	22%	3%
26	Raising plants	19%	13%	43 Knitting	19%	8%
27	Animal Care	17%	17%	57 Music-instrument	17%	3%
80	Athletic/sports	17%	8%	66 Travel	14%	11%
45	Handyman	17%	6%	26 Raising plants	14%	6%
67	Religious	15%	8%	56 Music-vocal	8%	6%
23	Camping	15%	8%	23 Camping	8%	3%
41	Cooking	10%	8%	38 Antique collection	8%	-
87	Fraternal Organizations	10%	-			

* Classified and coded according to the "Avocational Activities Inventory" Milwaukee Media for Rehabilitation Research Reports No.5, June 1968 (see Vol. II, chap.1)

I. Source of Information About Strokes and Knowledge and Use of Community Resources

There was no appreciable difference between experimental and control, or men and women clients on this item. It does not seem that many of the families had much, if any, knowledge of strokes and its effects before its occurance. About 20% knew of relatives, friends or co-workers who had suffered a stroke but most lacked even this minimum type of knowledge. After the stroke, it was usually the family doctor who described what had happened but fully half the clients either did not remember their doctor describing the stroke or felt the description was inadequate. Another 20% could not recall anyone explaining their illness to them. The figures seem to indicate a potential for paramedicals (e.g. therapists or visiting nurses) and the news media, (T.V., radio, newspapers) to disseminate information to the public.

Table 83: Source of Information About Strokes

Before Stroke			After Stroke		
Relatives	11	13%	Doctor	45	51%
Friends and Neighbors	8	9%	Therapists	13	15%
Co-workers	2	2%	News-media	11	13%
News-media	2	2%	Visiting nurse	5	6%
			Relatives	5	6%
			Friends and Neighbors	3	3%
			Caseworker-counselor	2	2%
Clients completing question:			88		

With the exception of the Visiting Nurse Association, the Senior Citizen Program and the Food Stamp Program, the resources available to citizens of Milwaukee County were not extremely well known. About half of the patients had heard of most of them but they seldom could remember where or when and even less frequently could accurately describe the program. Most of the patients were told about the Visiting Nurse by their family doctor and this was the only program that any number of clients actually used.

Recreation programs such as the Senior Citizen Centers, Golden Age Clubs, Bookmobile and talking books were familiar to about half of the families. Medical programs like the V.N.A., the University Dental Clinic, the T.B. Clinic and Immunization Clinic were also known by about half of the families. The Multiphasic Exam Program provided by the city of Milwaukee was recognized by only a quarter. The Food Stamps and Union Drug Services were known by half or more. Project Involve, a local poverty program to assist the elderly, was known to only a quarter of the patients.

Table 84: Milwaukee County Community Resources

Service or Program	Patients Knew About		Patients Have Used	
Visiting Nurse Association	54	82%	29	44%
Washington Park Senior Center	48	73%	5	8%
Local Senior Citizen Centers	48	73%	2	3%
Federal Food Stamp Program	41	62%	2	3%
Bookmobile	36	55%	2	3%
Golden Age Clubs	35	53%	1	2%
Marquette University Dental Clinic	35	53%	6	9%
Tuberculosis Clinic	34	52%	8	12%
Union Drug Stores	33	50%	11	17%
Immunization Clinic	28	42%	6	9%
Talking books	27	41%	6	9%
Wisc. Homestead Tax Credit	25	38%	3	5%
Project Involve	19	29%	1	2%
Mail Order Drug Services	18	27%	1	2%
Multiphasic Physical Exam	17	26%	1	2%
Project Involve Telephone Service	14	21%	-	-

Clients completing question: 66

J. Attitudes and Roles

The two tables below show that there were differences between the descriptions of men and women patients, both as made by themselves and their spouses. The men patients were more often described as not very interested in life anymore, unwilling to fight fate, and ready to give up except for the people helping them. The women patients were more frequently characterized as getting restless unless they kept busy, having their days pass slowly, feeling that being disabled can actually have advantages, and hoping that they will be as good as new before long. The men patients, more than the women patients, seemed to be self-conscious about their disability.* The spouses of women patients described their wives as feeling that people are uncomfortable with the disabled more often than did the spouses of men patients describe their husbands. Perhaps men, whether patients or spouses, are more disturbed by disability than are women. The figures in the tables seem to support this view.

Table 85: Differences between Men and Women Patients in Agreement to Patient Description Items at Followup

Statement	(N=24) Men Patients		(N=23) Women Patients		X^2	P
#16 Being disabled can have its advantages	3	13%	10	43%	5.63	.05
#2 I get restless unless I keep busy	12	50%	17	74%	2.84	.10
#11 Can't fight fate, accept life as it comes	19	79%	13	57%	2.77	.10
#69 Difficult to retain my interest in things	14	58%	8	35%	2.62	.10
#52 I'm not very interested in life anymore	7	29%	4	17%	1.55	.20
#8 I'd give up except for people helping	11	46%	6	26%	1.98	.20
#57 People are uncomfortable with the disabled	13	54%	8	35%	1.78	.20
#31 The disabled are different from other people	10	42%	6	26%	1.27	.30
#78 First thing people notice is my disability	14	58%	10	43%	1.04	.3

* The men more frequently said that the disabled are different, that people notice their disability, and that others are uncomfortable in the presence o disability.

Table 86: Differences Between Spouses of Men Patients and Spouses of Women Patients in Agreement to Patient Description Items at Followup

	N=25, Spouses of Men Patients		N=12, Spouses of Women Patients		χ^2	P
#11 Can't fight fate, accept life as it comes	16	64%	4	33%	3.07	.10
#42 He/she will be as good as new before long	9	36%	8	67%	3.07	.10
#57 People are often uncomfortable with the disabled	8	32%	7	58%	2.33	.15
#65 The days seem to pass slowly for him/her	15	60%	10	83%	2.01	.15
#8 He/she would give up except for people helping	14	56%	4	33%	1.67	.20
#52 He/she is not interested in life anymore	11	44%	3	25%	1.24	.30
#2 He/she gets restless unless busy	12	48%	8	67%	1.14	.30

From the next two tables, it can be seen that there was much more agreement between patient and spouse when a man was the patient than when a woman was. When a man was the patient, he and his spouse were usually forced to spend almost all their time together, thus allowing the spouse to get to know the patient's feelings all too well. Whereas when the wife is the patient, the husband would usually continue working if he could. It might be too, that women are simply more sensitive to, and perceptive of, the feelings of others. That would account for the greater success of wives in describing the patients feelings.

Patients described themselves as accepting life more often than their spouses described them this way. Spouses on the other hand, were more likely to describe the patients as lacking interest in life or things than were the patients. It could be that the extent of the patient's emotional investment in an activity passed unnoticed when his performance level dropped. Or it could be that the patients were satisfied with a lower rate of participation than before, but to the spouse it seemed that they were less interested.

Men spouses of women patients tended to describe their wives in much the same way as men patients describe themselves: feeling different from others, and feeling that others notice and are made uncomfortable by their disability. The women patients did not frequently describe themselves in this manner. However, women spouses of men patients were agreed that their husband patients felt this way. It could be that the results indicate a basic defference between male and female reactions to disability. In this case the husband spouses projected their own feelings when describing the patient. Or it could be that there was a difference between patient and spouse perceptions of patient feelings - in this case the husband misinterpreted, or the wife denied the true feelings of the woman patient.

Table 87: Differences Between Men Patients and Their Spouses in Agreement to Patients Descriptions at Followup

Statement	N=24, Men Patients		N=25, Spouses of Men Patients		X^2	P
#3 Important to learn to ignore your disability	17	71%	10	40%	4.70	.05
#57 People are often uncomfortable with the disabled	13	54%	8	32%	2.46	.15
#11 Can't fight fate, accept life as it comes	19	79%	16	64%	1.38	.25
#52 I/he is not interested in life anymore	7	29%	11	44%	1.16	.30

Table 88: Differences Between Women Patients and Their Spouses in Agreement to Patients Descriptions at Followup

Statement	N=23, Women Patients		N=12, Spouses of Women Patients		X^2	P
#65 The days seem to pass slowly for me/ her	11	48%	10	83%	4.14	.05
#31 The disabled are different from other people	6	26%	7	58%	3.51	.10
#78 The first thing people notice is my/ her disability	10	43%	9	75%	3.16	.10
#42 I/ she will be as good as new before long	8	35%	8	67%	3.23	.10
#11 Can't fight fate, accept life as it comes	13	57%	4	33%	1.70	.20
#57 People are often uncomfortable with the disabled	8	35%	7	58%	1.78	.20
#69 Difficult to retain my/her interest in things	8	35%	7	58%	1.78	.20
#16 Being disabled can have its advantages	10	43%	3	25%	1.15	.30

Husbands who have had a stroke, and their wives, gave a slightly different emphasis to the husband's roles than did the families where the wife has had the stroke. Stroke husbands were more inclined to rate companionship as the most important role for a husband to perform, and place support of the family as least important. Their wives agreed. But non-stroke husbands usually put support first and companionship second or third. Again, their wives followed suit. Men patients did not see helping with the housework as of first or last importance and neither did their wives. The women patients, however, put the husband's helping with the housework as last in importance where their husbands placed it second. This might have been defensiveness on the part of the wives.

Table 89: Husband's Marital Roles Ranked by Husbands at Followup

	N=15, Husband a Patient			N=9, Husband Not a Patient			N=24, All Husbands		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Be a companion to wife	53%	47%	-	22%	67%	11%	42%	54%	4%
Help with the house work if needed	7%	67%	26%	-	78%	22%	4%	71%	25%
Do own jobs around the house	20%	53%	26%	22%	44%	33%	21%	50%	29%
Support the family	20%	33%	47%	56%	11%	33%	33%	25%	42%

Table 90: Husband's Marital Roles Ranked by Wives at Followup

	N=18, Wife Not a Patient			N=8, Wife a Patient			N=26, All Wives		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Be a companion to wife	67%	22%	11%	25%	63%	12%	54%	35%	11%
Help with the house work if needed	11%	61%	28%	-	50%	50%	8%	57%	35%
Do own jobs around the house	11%	61%	28%	25%	63%	12%	15%	61%	23%
Support the family	11%	44%	44%	50%	25%	25%	23%	38%	38%

Husbands and wives, patients and non-patients, all agreed that the wife's place is in the home. All felt that the least important role she could perform is that of supporting the family. More importance was placed on her companionship than on homemaking, except by the woman stroke patient herself. The women patients gave first ranking to their homemaking role while their husbands, the men patients and the spouses of the men patients all did the reverse. It is interesting to note that when a man had the stroke, his role of supporting the family dropped to last rank; however, when a woman had a stroke, her role of homemaker continued to get a high ranking--still first in her own eyes, and 2-3rd in her husbands.

Table 91: Wife's Marital Roles Ranked by Husbands at Followup

	(N=13) Husband a Patient			(N=9) Husband not a Patient			(N=22) All Husbands		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Be a companion to husband	46%	38%	15%	67%	33%	-	55%	36%	9%
Be the homemaker	8%	92%	-	33%	56%	11%	18%	77%	5%
Practice the religion	31%	46%	23%	-	78%	22%	18%	59%	23%
Help support the family	15%	23%	62%	-	33%	67%	9%	27%	64%

Table 92: Wife's Marital Roles Ranked by Wives at Followup

	(N=21) Wife not a Patient			(N=8) Wife a Patient			(N=29) All Wives		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Be a companion to husband	43%	52%	5%	37%	63%	-	41%	55%	3%
Be the homemaker	23%	67%	10%	63%	37%	-	34%	59%	7%
Practice the religion	19%	48%	33%	-	75%	25%	14%	55%	31%
Help support the family	14%	33%	52%	-	25%	75%	10%	31%	59%

The patients and their spouses agreed that the primary role of the patient should be to help himself as much as possible. Neither emphasized a return to work for men patients, but about half of the women patients and their spouses mentioned a resumption of housekeeping as important. There seemed to be somewhat more emphasis, by patient and spouse, on the patient's entertaining himself. When a man was the patient, perhaps men patients felt more lost around the house during the day than did the women patients. While a few men felt that it was important for them to help with the housework, none of their spouses felt this way; conversely, while none of the women patients said it was most important for them to help the husband with his chores, almost a fifth of their spouses said exactly the opposite.

Table 93: Patient's Roles Ranked by Patients at Followup

	N=15, Men Patients			N= 8, Women Patients			N=23, All Patients		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Help self as much as possible	67%	33%	-	63%	37%	-	65%	35%	-
Entertain self when spouse is busy	7%	86%	7%	-	63%	37%	4%	78%	17%
Help spouse with his/her duties	13%	53%	33%	-	75%	25%	9%	61%	30%
Resume work/ homemaking	13%	27%	60%	37%	25%	37%	22%	26%	52%

Table 94: Patient's Roles Ranked by Spouses at Followup

	N=22, Spouses of Men Patients			N=9, Spouses of Women Patients			N=31, Spouses of All Patients		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Help self as much as possible	64%	27%	9%	55%	45%	-	61%	32%	6%
Entertain self when spouse is busy	32%	64%	5%	-	78%	22%	22%	68%	10%
Help spouse with his/her duties	-	77%	23%	22%	44%	33%	6%	68%	26%
Resume work/ homemaking	5%	18%	77%	22%	33%	44%	10%	22%	68%

The patients and spouses agreed on the roles for the spouse. Helping the patient and taking over those duties which the patient can no longer do were given most emphasis. When the patient was a man, somewhat less importance was attached, by both the patients and the spouses, to entertaining the patient. This was in accord with the previous table which indicated that men patients placed more emphasis on entertaining themselves than did the women patients. The patients, especially the women patients, seemed to place less value on the spouses understanding than did the spouses themselves. Perhaps the patients took understanding for granted and failed to realize the extra emotional demands they made on their partner. Either that, or the women patients were being realistic about the amount of understanding of which their husbands were capable.

Table 95: Spouse's Roles Ranked by Patients at Followup

	N=15, Men Patients			N=8, Women Patients			N=23, All Patients		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Help the patient when needed	53%	47%	-	50%	37%	13%	52%	43%	4%
Takes over duties patient can no longer do	33%	60%	7%	37%	63%	-	35%	61%	4%
Tries to understand if patient gets upset	13%	60%	27%	-	50%	50%	9%	56%	35%
Entertains and spends time with patient	-	33%	67%	13%	50%	37%	4%	39%	57%

Table 96: Spouse's Roles Ranked by Spouses at Followup

	N=22, Spouses of Men Patients			N=9, Spouses of Women Patients			N=31, Spouses of All Patients		
	1st	2-3rd	Last	1st	2-3rd	Last	1st	2-3rd	Last
Helps the patient when needed	45%	50%	5%	44%	33%	22%	45%	45%	10%
Takes over duties patient can no longer do	27%	55%	18%	22%	67%	11%	26%	58%	16%
Tries to understand if patient gets upset	18%	64%	18%	11%	78%	11%	16%	68%	16%
Entertains and spends time with patient	9%	32%	59%	22%	22%	56%	13%	29%	58%

K. Evaluation of Stroke Experience

Most of the patients felt that the greatest problem since the stroke had been the loss or impairment of physical functioning, together with its resulting decrease of mobility. Forty-eight percent gave replies of this sort. Another 15% felt that psychological effects, such as depression and self-pity, had been the greatest problem. The spouses mentioned the extra work most frequently (22%). Keeping the patient active and adjusting to changes in his/her personality were each mentioned by 13% of the spouses. About a third of the patients and the spouses declined to name a "greatest" problem.

Table 97: Greatest Problem Since the Stroke (In Rank Order)

Responses of Patients	Men Patients		Women Patients		All Patients	
Physical handicaps caused by stroke: use of arm, leg, speech etc.	13	26%	10	28%	23	27%
Lack of mobility, activity	9	18%	9	25%	18	21%
Depression or, self-pity psychological changes	6	12%	7	19%	13	15%
Self-care activities	1	2%	2	6%	3	4%
Finances	-	-	1	3%	1	1%
No answer	20	41%	7	19%	27	32%
Total	49	99%	36	100%	85	100%

Responses of Spouses	Spouses of Men Patients		Spouses of Women Patients		Spouses of All Patients	
Extra work, new duties	7	21%	3	25%	10	22%
Personality changes in patients	6	18%	-	-	6	13%
Keeping patient active	4	12%	2	17%	6	13%
Speech, communication	-	-	3	25%	3	7%
Being together all the time, being tied down	2	6%	1	8%	3	7%
Loss of faith	1	3%	-	-	1	2%
No answer	14	41%	3	25%	17	37%
Total	34	101%	12	100%	46	101%

Nearly 90% of the patients offered an opinion as to what had been the greatest help to them since the stroke. About half of the opinions concerned other people (31% family and friends, 14% medical personnel, 1% counselor-caseworker). Another 21% dealt with the physical disability itself (15% restoration of function, 6% use of aids or devices). Sixteen percent felt that the most important thing was the attitude or outlook of the patient himself (12% faith, 2% pride, 1% personality and 1% previous experiences). Seven percent that having a hobby or activity had been the greatest help.

Table 98: Greatest Help Since the Stroke (In Rank Order)

	Men Patients		Women Patients		All Patients	
Family and relatives	12	25%	6	17%	18	21%
Restoration of function to affected parts (at least partial)	8	16%	5	14%	13	15%
Medical personnel (doctors, nurses, therapists)	6	12%	6	17%	12	14%
Faith, ability to accept fate	6	12%	4	11%	10	12%
Friends, other people	4	8%	4	11%	8	9%
Activities, hobbies	4	8%	2	6%	6	7%
Medical devices or aids (canes, walkers)	2	4%	3	8%	5	6%
Sense of pride, determination	-	-	2	6%	2	2%
Change in personality	1	2%	-	-	1	1%
Caseworker-counselor	1	2%	-	-	1	1%
Past personal experience with disability	1	2%	-	-	1	1%
No answer	4	8%	4	11%	8	9%
Total	49	99%	36	101%	85	98%

The family doctor was named by 55% of the people as the professional person who had been most important to the family since the stroke. Paramedical professionals (therapists, visiting nurses) were named another 11% of the time. Non-medical personnel were viewed as most important by only 7% of the families. However, as with the question regarding the most important person at Curative (see Table 104) the medical people are described as playing an expressive, rather than an instrumental role.* Three times as many patients described the doctor, nurse or therapist as being "most like a" friend, father or brother then described them as a doctor, teacher or professional.

* The dichotomy between instrumental and expressive roles is relevant here. See Parsons and Bales, Family, Socialization and Interaction Process, Free Press, 1955, Chapter 6, "Role Differentiation in the Nuclear Family - A Comparative Study" p. 307.

Table 99: Most Important Professional Person Since the Stroke (In Rank Order)

	Men Patients		Women Patients		All Patients	
Family doctor	24	49%	23	64%	47	55%
Visiting nurse	2	4%	3	8%	5	6%
Therapist and Nursing home	1	2%	1	3%	2	2%
Speech Therapist at Curative	1	2%	1	3%	2	2%
Wife/Husband	1	2%	1	3%	2	2%
Activities Program counselor	1	2%	-	-	1	1%
Caseworker Counselor	1	2%	-	-	1	1%
Pastor	1	2%	-	-	1	1%
Landlord	1	2%	-	-	1	1%
No answer	16	33%	7	19%	23	27%
Total	49	100%	36	100%	85	98%

The patients' comments on what is important in adjusting to a stroke can be dichotomized: those reflecting an active as opposed to those reflecting a more passive outlook. The relative proportions of each were about the same for both men and women patients: 35% passive-accept conditions, have humor, faith, listen to others; 28% active-ignore conditions, stay active, do exercises. The spouses who were available for comments (more often the case if the patient was a man) usually urged patience and acceptance, if they answered at all.

Table 100: What is Important in Adjusting to a Stroke (In Rank Order)

Responses from Patients	Men Patients		Women Patients		All Patients	
Accept condition, be patient	11	22%	10	28%	21	25%
Ignore conditinn, be determined	6	12%	6	17%	12	14%
Stay active, alert, occupied	4	8%	6	17%	10	12%
Have sense of humor	4	8%	1	3%	5	6%
Have faith	-	-	3	8%	3	3%
Enter rehabilitation program, do exercises regulary	2	4%	-	-	2	2%
Listen to others	1	2%	-	-	1	1%
No answer	21	43%	10	28%	31	37%
Total	49	99%	36	101%	85	100%

Responses from Spouses *	Spouses of Men Patients		Spouses of Women Patients		Spouses of All Patients	
Accept patient's condition	14	41%	3	25%	17	37%
Have patient learn to do new things	1	3%	2	17%	3	7%
Accept help from others	-	-	1	8%	1	2%
No answer	19	56%	6	50%	25	54%
Total	34	100%	12	100%	46	100%

* Figures are for only those cases where spouse was present during followup interview.

Half the patients and two-thirds of the spouses did not describe a "hindrance" to adjustment. Those who did mentioned a wrong attitude most frequently: 22% of the patients, 13% of the spouses. The next most frequently mentioned hindrances were a lack of activity for patients (19%), and a lack of social life for spouses (11%). No patient, and only 4% of the spouses, specifically mentioned the physical condition of the patient itself as a hindrance.

Table 101: Hindrances to Adjustment After a Stroke (In Rank Order)

Responses of Patients	Men Patients		Women Patients		All Patients	
Wrong attitude: expect too much, self-pity, depression	12	25%	7	19%	19	22%
Lack of activity, decrease in mobility	8	16%	8	22%	16	19%
Lack of understanding from others	4	8%	3	8%	7	8%
No answer	25	51%	18	50%	43	51%
Total	49	100%	36	99%	85	100%

Responses of Spouses	Spouses of Men Patients		Spouses of Women Patients		Spouses of All Patients	
Wrong attitude towards patient: expect or help too much	5	15%	1	8%	6	13%
Lack of social life; can't get out	3	9%	2	17%	5	11%
Extra work, new duties	2	6%	1	8%	3	7%
Physical condition of patient	1	3%	1	8%	2	4%
No answer	23	68%	7	58%	30	65%
Total	34	101%	12	99%	46	100%

The advice of stroke patients to other stroke victims falls into three general categories: acceptance and patience (25%); determination, keep busy (25%); accept outside help (26%). Another quarter had no special advice to give.

Fifty-two percent of the spouses of stroke victims counselled patience, faith or understanding, compared to 17% for keeping patient active and busy. The spouses were proportionately more willing to give advice than the patients. One spouse had the ultimate solution: "stay healthy and avoid a stroke."

Table 102: Advice for New Stroke Patients and Their Families (In Rank Order)

Responses of Patients	Men Patients		Women Patients		All Patients	
Accept situation, be patient	12	24%	6	17%	18	21%
Never give up, patient should do as much as possible	7	14%	6	17%	13	15%
Patient will need and should accept advice and help	6	12%	6	17%	12	14%
Seek medical-therapeutic aid find out about stroke effect	8	16%	2	6%	10	12%
Stay active, keep busy	6	12%	2	6%	8	9%
Have faith	1	2%	2	6%	3	3%
No answer	9	18%	12	33%	21	25%
Total	49	98%	36	102%	85	99%

Responses of Spouses	Spouses of Men Patients		Spouses of Women Patients		Spouses of All Patients	
Accept situation, have patience	10	29%	6	50%	16	35%
Keep patient active, make him help himself	7	21%	1	8%	8	17%
Understand patient and his problems	5	15%	2	17%	7	15%
Expect extra work, many problems	4	12%	1	8%	5	11%
Maintain social life, visit people	2	6%	2	17%	4	9%
Have faith	-	-	1	8%	1	2%
Stay healthy, avoid stroke	-	-	1	8%	1	2%
No answer	6	18%	-	-	6	13%
Total	34	101%	12*	116%	46*	104%

* Two spouses of women patients gave two answers each

L. Evaluation of Rehabilitation Program at Curative Workshop

Table 103 below shows that overall, the patients seem to feel that Physical Therapy was the single most important activity at Curative. Perhaps this is because it dealt most directly with their affected part. Also, it was the one therapy that almost all patients were exposed to. While only 9% of the total number of patients felt the Activities Program was the most important 47% of those exposed to the Program named it. The same is true with Speech Therapy. Not all patients were given Speech Therapy; about a third (33%) of those who were, said it was the most important. There was an interesting difference between men and women. Men were significantly more likely than the women to select the Activities Program and a chance to get out of the house as important (24% vs. 3%, $X^2 = 7.86$, $P.<.01$).

Table 103: Most Important Activity at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Physical Therapy	21	43%	18	50%	39	46%
Speech Therapy	6	12%	7	19%	13	15%
Occupational Therapy	4	8%	6	17%	10	12%
Activities Program	7	14%	1	3%	8	9%
Chance to get out of house	5	10%	-	-	5	6%
No answer	6	12%	4	11%	10	12%
Total	49	99%	36	100%	85	100%

The table following shows that just as Physical Therapy was viewed as the most important activity so were the Physical Therapists seen as the most important people. As many patients (31%) chose a P.T. as most important person as chose all the others combined (32%). More than a third (38%) were not able to single out any one individual as most important. After choosing a most important person half (51%) described him/her as "most like a" friend, another 21% as a brother/sister, mother or daughter, and only 19% described the most important person as most like a teacher. This seems to indicate that despite the patients' verbal depiction of the medical-therapy aspect as most important they respond primarily to the expressive aspects of the work role. Here again there was a difference between men and women. Men were more likely to choose a non-medical person as most important than were women. Only one of the 22 women responding chose a non-medical person, whereas 10 of 31 men making a choice selected non-medical personnel (counselor, caseworker, fellow-patient etc.).

Table104: Most Important Person at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Physical Therapist	12	24%	14	39%	26	31%
Speech Therapist	6	12%	6	17%	12	14%
Activities Program Counselor	4	8%	-	-	4	5%
Caseworker Counselor	3	6%	1	3%	4	5%
Occupational Therapist	3	6%	-	-	3	4%
Transportation Coordinator	2	4%	-	-	2	2%
Fellow-patient	1	2%	-	-	1	1%
Doctor	-	-	1	3%	1	1%
No answer	18	37%	14	39%	32	38%
Total	49	99%	36	101%	85	101%

Only half of the patients named a "least important"activity, most replying that "all were important". When an answer was given, it was most likely to be occupational therapy, about a quarter of all patients choosing this. They seemed to feel that the activities in O.T. were unrelated to their problem. They did not understand how "playing with blocks" or working a printing press could be useful to them. This seems to follow the pattern established in previous questions where the patients continually indicated that they perceived Curative as a place that would work on, and restore function to, their affected arm or leg.

Table105: Least Important Activity at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Occupational Therapy	11	22%	9	25%	20	24%
Physical Therapy	7	14%	2	6%	9	11%
Speech Therapy	5	10%	3	8%	8	9%
Games in Activities Program	1	2%	-	-	1	1%
No answer	25	51%	22	61%	47	55%
Total	49	99%	36	100%	85	100%

Most of the patients (52%) were unable or unwilling to recall a "best" experience. Of those who did, 28% selected more social, interaction type experiences than medical or therapy-related ones (20%). Here again there was a difference between the men and women. Thirty-seven percent of the men described "social interaction" type experiences (getting out of house, attitude of staff, increase of confidence) while only 16% mentioned medical - therapy situations (learning to walk, O.T., P.T., Speech). For the women the percentages were 17% and 25% respectively. These differences tend toward significance, $X^2=3.35$, $P < .10$.

Table 106: Best Experience at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Getting out of house, meeting people	10	20%	2	6%	12	14%
Learning to walk again	6	12%	4	11%	10	12%
Attitude/help of staff	5	10%	2	6%	7	8%
Increase in self confidence, feeling of independence	2	4%	2	6%	4	5%
Speech Therapy	1	2%	2	6%	3	4%
Occupational Therapy	-	-	3	8%	3	4%
Activities Program	1	2%	-	-	1	1%
Physical Therapy	1	2%	-	-	1	1%
No answer	23	47%	21	58%	44	52%
Total	49	99%	36	101%	85	101%

Two-thirds of the patients did not care to describe a "worst" experience. Of those who did the most frequently mentioned were of the "personal indignity" kind (14%). Such things as "always asking personal questions", "doing kid's stuff", or "being rushed all the time" were put in this category.

Table 107: Worst Experience at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Personal Indignities: feeling rushed, personal questions, childish activities, different therapists every time, etc.	7	14%	5	14%	12	14%
Physical discomfort: pain in shoulder, too hot or cold, falling down, etc.	5	10%	3	8%	8	9%
Logistical arrangements: parking, transportation, bills, etc.	4	8%	2	6%	6	7%
Stopping therapy	-	-	3	8%	3	4%
No answer	33	67%	23	64%	56	66%
Total	49	99%	36	100%	85	100%

Less than a quarter of the patients voiced a feeling that anything had been lacking at Curative. When they did it was invariably expressed in physical terms: length of treatment, emphasis of treatment or number of staff.

Table 108: What was Lacking at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
Enough therapy to have effect	6	12%	3	8%	9	11%
Enough staff: too many interns	3	6%	2	6%	5	6%
Proper emphasis in therapy: whirlpool in P.T.; self-care in O.T.; work in Activities Program,; a weekend program	3	6%	1	3%	4	5%
Physical facilities: toilets, chairs, coffee, etc.	3	6%	-	-	3	4%
No answer	34	70%	30	83%	64	75%
Total	49	100%	36	100%	85	101%

Slightly more than half the patients volunteered suggestions as to what should be changed at Curative. The most frequent response concerned the frequency or the type of therapy sessions (29%). Another 18% of the patients talked about improved personal contacts between patients and staff (more individual attention, fewer personal questions, etc.). The remaining 9% replied in terms of physical facilities (parking, etc.) including one woman who was disgruntled over the coffee.

Table 109: What Should be Changed at Curative (In Rank Order)

	Men Patients		Women Patients		All Patients	
More individualized program: more staff, fewer students, allow patients more choice	8	16%	5	14%	13	16%
More frequent therapy sessions	6	12%	5	14%	11	13%
Different activities in therapy: more work in Activities Program, more realistic activities in O.T.	7	14%	2	6%	9	11%
Better facilities; new building more parking	5	10%	2	6%	7	8%
Fewer therapy sessions	3	6%	-	-	3	4%
Fewer personal questions	-	-	2	6%	2	2%
Whole program	2	4%	-	-	2	2%
Coffee	-	-	1	3%	1	1%
No answer	18	37%	19	53%	37	43%
Total	49	99%	36	102%	85	100%

Followup Findings: Summary and Implications

Summary	Implications
Methodology	
A structured interview followup was completed with 88 patients which was 67% of the original project population. 19 (14%) of 132 patients had died. 17 (13%) had moved and could not be located. 8 (6%) refused to cooperate.	
The interviews were held between 11 and 37 months after the patient was admitted to the rehabilitation program. Average time since admission was 22 months.	Any temporary, as against permanent, influence of the rehabilitation program should have subsided.
A. Housing: Living Arrangements	
69% lived with spouse only or with spouses and children.	The nuclear family is the dominant form of living style for stroke patients.
The 16 (12%) who lived alone before the stroke were reduced to 6(6%) who lived alone after the stroke.	Some stroke patients can live independently.
8 patients (8%) were in a nursing home at followup.	Fewer patients than was anticipated had to move into a nursing home.
Physical Adaptation Made in the Home	
About 70% had made physical changes in the household because of the stroke. Of these, about one-third were furniture rearrangement or removal of rugs. About 15% of the adaptations (usually grab bars or kitchen devices) were suggested by rehabilitation professionals.	Suggesting adaptations is a useful function of rehabilitation professionals.
B. Finances	
Half of the families had incomes of less than $4,000 annually and half had less than $1,000 in savings.	This is living at the poverty level with inadequate reserves for future crises.

Summary	Implications
B. Finances - Continued	
Before the stroke about two-thirds derived their income from wages and salaries and one-third were on social security. Now 72% received social security and only 30% relied on wages and salaries.	Any medical research money spent by the government which reduced the incidence of stroke or delayed the occurrence of stroke until an older age would be repaid through more income tax receipts and fewer social security disability and welfare payments.
The number receiving public assistance jumped from 3 (4%) to 7 (9%).	
A majority were forced to spend at least part of their savings to pay for incurred expenses. One-third or more cut back expenses for socializing, recreation, clothing and food. Less than 10% were forced to more drastic steps.	Hospitalization, health, and income protection insurance policies with larger benefits for catastrophic illness are needed.
All but one family had some form of health insurance and almost all of those eligible had used medicare.	
C. Employment Status	
Before the stroke two-thirds of the men and one-third of the women patients were working full time. At followup only 4% of the men patients and none of the women patients had full time work. Another 5% of each had part time work. Seven (14%) of the men patients and 2 (5%) of the women patients have attempted to find employment, usually from former employers. Another 12% of the men and 5% of the women patients said they still planned to return to work eventually.	The state of the Milwaukee Labor Market changed radically during the period of the project. Seasonally adjusted unemployment changed from 2% in September, 1966 to 3.4% in January, 1970 to 4.1% in May, 1970 and finally to 5.4% in May, 1971. Applicants who are marginally employable at a 2% rate are usually unemployable at a 5.4% rate.
The percentage of working wives of men patients decreased from before to after the stroke.	As a group, women do not reverse their sex role and become the wage earner to augment the family income.

Summary	Implications
D. Performance in Activities of Daily Living as measured by the Milwaukee Activities of Daily Living Inventory (MADLI) at Followup	
Forty-eight patients rated themselves. Three-fourths saw themselves as independent on each item. Dialing phone was highest with 93%; Climbing or descending stairs was lowest with 73%. Men and women were about equal in appraising their own performance.	
As a group, spouses tended to rate patients lower on being independent by 8% to 26% than the patients rated themselves.	This may be highly significant in family decision-making concerning leaving the patient alone.
For twenty-three couples where both patient and spouse rated the patient there was high agreement. Transferring (83% agreement) and walking (87% agreement) were lowest in agreement but both these figures are above the highest rates of agreement between patient and spouse on admission to the Agency. At admission the couples (not necessarily the same couples) agreed only 70% of the time. At followup it was 91% of the time.	Improved inter-spouse agreement on what the patient can and cannot do is probably a good measure of becoming more realistic.
When there was a disagreement, the patient usually gave himself the higher rating.	For the best estimate of abilities, reports from both patient and spouse should usually be secured.
E. Performance of Household Tasks	
On 21 household tasks, most of the activities tend to be divided along sex lines. Wives have primary responsibility for housework and family affairs in general. Husbands have the primary concern for yard work and minor repairs.	
Specific tasks were almost always done by one spouse or the other, while the more general decision-making areas of planning, recreation and socializing were joint projects.	

Summary	Implications
E. Performance of Household Tasks - Continued	
Changes in Performing Household Tasks	
When the wife was the patient more changes occurred in who performed household tasks. One-third or more of the families with women patients had to make some adjustment in each of the 21 activities.	When the wife is the patient, the family is more apt to need housekeeping care: either volunteer help or paid professional service.
When the husband was the patient, there were only 8 activities in which more than one-third of the families were affected.	When the husband is the patient, the family is more apt to need money.
On the average, a stroke to a woman resulted in 11 changes in the performance of household duties, for a man patient only 7 activities were affected. This difference was statistically significant ($t=2.95$, $p < .01$).	
When the man was the patient, what he stopped doing his wife started to do.	
When the woman was the patient, husbands were not able to take over all of their wife's tasks and frequently a daughter would help.	
F. Patterns of Help	
The following report excludes help given by spouse. Help given varied according to sex of the patient.	
The burden fell most heavily on one person - for men patients, 31% of the time the help was given by one son and 31% of the time by one daughter.	Psychological problems frequently arise when one person shares the entire burden of another's care.
For women patients, 43% of the help was given by one daughter and 14% by one sister.	Patient care is predominantly a part of the feminine rather than the masculine role.

Followup Findings - Continued

Summary	Implications
F. Patterns of Help - Continued	
Help given by someone outside the family amounts to only 11% for men patients, 16% for women patients. Neighbors account for 7% and 8% respectively.	There appears to be no breakdown in the mutual aid patterns of these urban families. The problem is in the breakdown of neighborhood aid. Since neighbors by definition live close-by, but family members are not necessarily so located, neighbors are in a better position to help.
Forms of help given also varied by sex of patient. Men patients received 25% of their help with transportation, 18% with shopping and 14% as patient care. Women patients received 16% of their help as patient care, 16% with shopping, and 16% with transportation.	
Patterns of help were reciprocal. Whom the patients helped rather closely followed the pattern of who helped them. This says nothing about either the quality or amount of help given, only the distribution of help coming from and going to different categories of significant others. Thus, one daughter and one son headed the list of those receiving help.	Most patients need to develop more extensive patterns of mutual aid to meet their needs.
The most frequent kind of help given by patients was in child care, doing chores, providing living accomodations, financial assistance, and advice.	There may be opportunities for patients to contribute in the area of child care to a much greater extent than has been the practice.

Summary	Implications
G. Social Contacts	
This includes the spouses as one of those seen. Patients saw on the average 2.57 people once a week or more. Men averaged significantly more contacts a week than women ($t = 2.20$, $p < .05$).	
For both sexes, over 80% of the people seen once a week or more were family members. Sixty-five per cent of those seen were a spouse or child. Daughters were seen exactly twice as often as sons.	The family social network continues to support the individual. The community network of social bonds has greatly diminished.
Only 9% of the people seen once a week or more were neighbors. Only 10% were friends. One per cent were co-workers.	Combining friends, co-workers and neighbors, we find 20% are non-family contacts. Of these, the neighbors, because of geographic propinquity, are the most useful for giving practical assistance at the right time.
Only about 10% of the patients maintained any close relationship with other stroke patients once they left the Agency. Twenty-three per cent reported having contacts, but only infrequently in their home or the other patient's home.	There is a need for programs to ease the patient's transition from dependent patient to a peer in social relationships.
H. Avocational Activities	
Men and women patients did not differ in the rank order in which they selected avocational activities. The pre-stroke rank order also was unchanged at the time of the follow-up.	
TV watching, card playing, and reading were the most frequently selected and in that order. The percentages of people doing each remained fairly constant both between sexes and before and after the stroke.	Avocational counseling may well start by helping patients enlarge and enrich their activities within these areas.

Summary	Implications
H. Avocational Activities - Continued	
Hunting and fishing for men and knitting and sewing for women decreased sharply from before the stroke to the time of followup.	
Before the stroke men averaged about half an activity more than women. At followup they were about equal.	Since women had fewer activities to begin with, they stopped fewer after the stroke.
It was unusual for a patient to continue an activity at a reduced rate. They usually either stopped completely (40% of pre-stroke activities) or continued at the same or even an increased level. Only about 13% of pre-stroke activities were continued at a reduced rate.	
Only 12% of the activities being performed had been started since the stroke. Women were more apt to do this (18%)than men (7%).	New techniques in avocational counseling are needed to motivate the patient to try new things.
I. Knowledge and Use of Community Resources	
Sources of Information about Strokes	
Before the stroke happened to them about 25% of the families knew of relatives, friends, or co-workers who had suffered a stroke.	
After the stroke it was usually the family' doctor who described what had happened, but half of the patients either did not remember their doctor describing the stroke or felt that the description was inadequate.	It is no news that medical counseling should be improved, whether done by physician, nurse, medical social worker, or some other member of the medical team.
Twenty per cent could not recall anyone explaining the stroke to them.	There is a real need for better dissemination of information about strokes.

Summary	Implications
I. Knowledge and Use of Community Resources - Continued	
Sources of Information about Strokes - Continued	
The caseworker/ counselors were mentioned by only 2 families (2%).	This indicated that they were not doing a good job of dispensing information about strokes. In retrospect it appears that an earlier contact with a small sample of patients should have been made to determine th effectiveness of the counselors in giving information about the stroke.
Information About the Community	
Most of the patients were told about the Visiting Nurse Program by their family doctor and this was the only program that many patients actually used.	Considering the poverty level at which half of the stroke families live, it is important that they know about and secure as many free and low cost health services as possible.
Medical programs such as the VNA, the Marquette University Dental Clinic, the T.B. Clinic, and the Immunization Clinic were also known by about half of the families. Food Stamps and the Union Drug Services were known by half. The City of Milwaukee Multiphasic Exam Program and Project Involve, a program to assist the elderly, were known to one-fourth.	
Recreation programs such as the Senior Center, Golden Age Clubs, Bookmobile and Talking Books were familiar to about half of the patients.	Avocational counseling should make them more fully aware of the educational and recreational opportunities in the community.

Summary	Implications
J. Attitudes and Roles (based on responses to standardized attitude inventories)	
Men patients were described as: not very interested in life anymore, unwilling to fight fate, ready to give up except for the people helping them, feeling self-conscious about their disability, feeling that the disabled are different, feeling that people notice their disability, feeling that other people are uncomfortable in the presence of their disability.	Men and women stroke patients have different attitudes towards their disability and in general women seem to adjust better.
Women patients were described as: getting restless unless busy, having days pass slowly, feeling that being disabled can have advantages, hoping that they will be as good as new before long.	
There was more agreement between patient and spouse when a man was the patient.	When the patient is a man, the spouses are likely to spend more time together.
Patients described themselves as accepting life more often than their spouses described them this way.	
Stroke patient husbands were inclined to rate companionship as the most important role for a husband to perform, and their wives agreed.	This is a realistic and desirable psychological adjustment.
Non-stroke husbands usually put support first and companionship second or third, and their wives agreed.	

Summary	Implications
J. Attitudes and Roles - Continued	
Women patients put the husband's helping with housework as least in importance whereas their husbands placed it second.	Wives resist intrusion into their homemaker roles.
Husbands and wives, patients and non-patients all were agreed that the wife's place is in the home. All felt that the least important role she could perform is that of supporting the family.	The new values of the Women's Liberation Movement have not touched these families.
When a man had the stroke, his role of supporting the family dropped to last rank; however, when a woman had a stroke, her role of homemaker continued to get a high ranking, both by herself and her husband.	This is realistically related to the probability of being able to continue in the role.
The women stroke patients ranked their homemaking role higher than their companionship role in contrast to the relative rankings given these items by all the men and the spouses of men patients.	There is a rigid, compulsive attachment to the homemaker role among these women patients.
While a few of the men felt that it was important for them to help with the housework, none of their spouses felt this way.	
None of the women patients felt was most important for them to help the husband with his chores although almost one-fifth of the husbands thought it was.	There is a great reluctance to cross over sex roles.

Summary	Implications
K. Evaluation of Stroke Experience	
Most of the patients named the loss or impairment of physical functioning as the greatest problem of the stroke, followed by psychological effects. The spouses mentioned the extra work most frequently.	
About half of the patients thought that the greatest help to them since the stroke had been other people including: family and friends 31% medical personnel 14% counselor/ caseworker 1%	It had been anticipated that the counselor/ caseworker would have more often been perceived as the most helpful.
The patients named the most important professional person since the stroke in this order: family doctor 55% paradedical professionals 11% nonmedical personnel 7%	
Caseworker/ counselor was named only 1% of the time.	Again the counselor/ caseworker comes out a rather poor last.
Three times as many patients described the doctor, nurse or other therapist as being "most like a" friend, father, or brother than described them as a doctor, teacher, or professional.	Patients resist the affectively neutral role of professionals.
Patients split on describing what is most important in adjusting to a stroke: passive (accept conditions) 35% active (ignore conditions) 28%	Which coping mechanism is used probably is determined by pre-stroke personality and adjustment patterns.
Hinderances in adjustment to stroke were described as: wrong attitude 22% lack of activity for patients 19% lack of social life for spouses 11%	
Advice for other stroke patients was: acceptance and patience 25% determination, keep busy 25% accept outside help 26%	Apparently, patients do not perceive one coping style as optimal.
Spouses advised: patience, faith or understanding 52% keep patient active and busy 17%	The passive, coping solution seems to be valued over the active for spouses, if not for patients.

Summary

Implications

L. Evaluation of Rehabilitation Program at Curative Workshop

Patients' perceptions of their Rehabilitation Program at Curative Workshop are indicated below. This is not corrected for how many patients were exposed to each activity. Responses which amounted to less than 3% were omitted, as was the percentage not answering.

Most Important Activity at Curative:

Physical therapy	46%
Speech therapy	15%
Occupational therapy	12%
Activities program	9%
Chance to get out of the house	6%

Generally rellects the number of patients who were exposed to each of these programs.

Men were significantly more likely to select the Activities Program and a chance to get out of the house. (24% vs. 3%, $\chi^2 = 7.86$, $p < .01$).

This is in accord with general masculine - feminine role norms.

The most important person chosen was:

Physical therapist	31%
Speech therapist	14%
Activities program counselor	5%
Caseworker/ counselor	5%
Occupational therapist	4%

Fifty-one per cent of those choosing a most important person described him/ her as most like a friend, another 21% as a brother/ sister, mother or daughter.

This seems to indicate that despite the patients' verbal depiction of the medical-therapy aspect as the most important, they respond primarily to the expressive aspects of the work role.

Least Important Activity was:

Occupational therapy	24%
Physical therapy	11%
Speech therapy	9%

Patients seemed to perceive Curative as a place that would work on, and restore function to, their affected arm or leg. Physical therapy is seen as fulfilling this function more than occupational therapy.

Summary

Implications

L. Evaluation of Rehabilitation Program at Curative Workshop - Continued

Best Experience at Curative:

Getting out of house, meeting people	14%
Learning to walk	12%
Attitude/ help of staff	8%
Increase in self-confidence, feeling of independence	5%
Speech therapy	4%
Occupational therapy	4%

This is in accord with commonly expressed patient sentiments.

Worst Experience at Curative:

Feeling rushed, personal questions, childish activities, different therapists every time	14%
Too hot, too cold, etc.	9%
Parking, transportation, bills, etc.	7%
Stopping therapy	4%

These realistic, practical problems will shortly be corrected by a move to a new building.

Only one-third of the patients mentioned a "worst" experience.

These and the following responses suggest a reasonable degree of satisfaction with the program.

What was lacking at Curative:

Enough therapy to have effect	11%
Enough staff; too many interns	6%
Proper emphasis in therapy	5%
Physical facilities	4%

Less than a quarter of the patients answered that anything had been lacking.

What should be changed at Curative:

More individualized program, more staff, fewer students	16%
More frequent therapy sessions	13%
Different activities in therapy, more work in Activities Program, more realistic activities in O.T.	11%
Better facilities	8%
Fewer therapy sessions	4%

Slightly more than half volunteered suggestions for improvements.

AUTHOR - SUBJECT INDEX FOR VOLUME I

(note: materials appearing in the Summary and Implications sections at the end of chapters 2, 3, 4, 5, and 6 are not indexed)

Author - Subject	Page (s)
Activities of Daily Living	28, 29, 30, 31, 32, 66, 81, 82, 83
Age	24
Agencies	57
Aphasia	25
Artes, R.H.	27, 75
Attitudes, patient	32, 53, 54, 75, 98, 106, 109
spouse	32, 98, 109
Avocational Activities	22, 69, 70, 94, 95
file	14
Inventory	14, 95
Bales	106
Ballweg	84
Behavior, patient	53, 54, 75
Blood, R.	32, 75, 84
Casework	16, 45, 50, 60, 62,
Centers, R.	32
Children	19, 20, 55, 76
Christopherson	75, 84
Churches	4, 61, 62
Collateral Contacts	47
Community Satellite Centers	14, 60, 61, 62
Content Analysis	53 - 58
Counseling	16, 45, 46, 48, 49, 50, 51, 52, 55, 56, 62, 72, 73
Counseling Reports	48, 53
Education	26
Employment	27, 28, 66, 80
Family Members Contributing	19, 20, 21, 23, 87
Financial Status	78, 79
Followup	16, 75 - 115
Goals	33, 34

AUTHOR - SUBJECT INDEX FOR VOLUME I - CONTINUED

Author - Subject	Page (s)
Hemiplegia, type of	24
Hollingshead Two Factor Index	27
Household Adaptations	65, 77
Household Tasks	66, 67, 84, 85, 86, 87
Interviews	16, 46, 75
Isolation of Patients	21
Living Situation of Patients	19, 20, 23, 26, 76
Marital Status	25
Milwaukee Activities of Daily Living Inventory (MADLI)	14, 16, 19, 28, 29, 30, 31, 32, 66, 81, 82, 83
Neighborhoods	21, 61, 62.
Parsons	106
Progress Reports	17
Residence of Patients	19, 23, 25
Roen	75
Roles	32, 33, 35, 36, 37, 38, 39, 40, 98, 100, 101, 102, 103, 104
Sex	24, 84, 89
Social Class	27
Social Worker	15, 16
Social Work Students	4, 61, 62, 63
Spouses	19, 28, 32, 33, 34, 39, 40, 54, 76, 80, 82, 84, 93, 98, 99, 100, 102, 103, 104, 108, 109, 110
Straus, A. B.	48
Stroke Clinic	14
Transportation	22, 60, 61, 62, 89, 91
Wolfe, D. M.	32, 75, 84

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EDUCATING STROKE PATIENT FAMILIES

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CURATIVE WORKSHOP
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EDUCATING STROKE PATIENT FAMILIES

Final Report

VOLUME II

Robert P. Overs, Ph.D. and John R. Healy

July, 1971

Research Department

CURATIVE WORKSHOP OF MILWAUKEE

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The MILWAUKEE MEDIA FOR REHABILITATION REPORTS is designed to make available rehabilitation research information which is not easily disseminated through the usual publication channels. Some of these reports will be concerned with methodological notes and techniques which are too specific in interest to appear in regular journal publications.

Others, suitable for journal publication, will be published in the MILWAUKEE MEDIA when it appears desirable to avoid the current publication lag.

A third type of material to be published will be studies geographically related to Milwaukee and Wisconsin which, while important to that area, may have limited significance in other parts of the country.

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This Report is published in three volumes, of which this is Volume II.

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TABLE OF CONTENTS

Chapter	Title	Page
	Table of Contents	3
	List of Forms	4
	Introduction to Volume II	5
1	Instrumentation	6
	A. Avocational Activities: Inventory, File and Descriptions	6
	B. Milwaukee Activities of Daily Living Inventory (MADLI)	7
	C. Suinn-Feldman Rehabilitation Self-Description Scale	15
	D. Description by Spouse Scale	21
	E. Roles Inventory	33
	F. Inventory of Goals	45
2	Miscellaneous Innovations	48
	Innovations in Casework Mechanics	48
	Recording Forms as Conceptual Tools	49
3	Research Utilization	52
4	Discussion and Conclusions	53
5	Summary and Implications	60
	Author - Subject Index	65
	Appendix	i
	Table of Contents	i
	List of Tables and Forms	ii

LIST OF FORMS

Form Title — Page

Chapter 1 - Instrumentation

Milwaukee Activities of Daily Living Inventory.....10

Milwaukee Activities of Daily Living Inventory - Short Form.....14

Suinn-Feldman Rehabilitation Self-Description Scale.....16

Description by Spouse Scale.....22

Suinn-Feldman Self-Description - Short Form.....29

Suinn-Feldman Spouse Description - Short Form.....31

Marital Roles Inventory - Husband's Roles.....34
Wife's Roles.....35

Hurvitz Marital Roles Inventory - Husband's Roles (short form).....37
Wife's Roles (short form).....38

Roles Inventory - Husband's Roles.....40
Wife's Roles.....41

Stroke Roles Inventory - Husbands' Roles (short form).....43
Wife's Roles (short form).....44

Inventory of Goals - Wives' Goals for Husbands.....46
Husbands' Goals for Wives.....47

Chapter 2 - Miscellaneous Innovations

Family Tree.....50

Transportation Schema for Local Travel.....51

INTRODUCTION TO VOLUME II

Volume II is the second volume of the final report of a project entitled "Educating Stroke Patient Families". Volume I reports on the design, methodology, and outcome of a four year project to determine the effect of intensive counseling and/or casework services in maintaining and possibly improving patient gains after the completion of a rehabilitation program.

An intensive followup of patients and families recorded significant information about patterns of housing status, financial status, remaining patient capacity in activities of daily living, role changes in activities of daily living, patient knowledge and use of community resources, patient social contacts, patients' evaluations of their stroke experience, and finally patients' evaluations of the rehabilitation program.

In Volume II the instrumentation developed for the Project is discussed in Chapter 1, including a classification system for avocation activities, and and avocational activities community resources file.

There is also a description of a new activities of daily living inventory and three attitude inventories. These include the Suinn-Feldman Rehabilitation Self-Description Scale and its derivative entitled the "Description by Spouse Scale." Also included is the Hurvitz Marital Roles Inventory and adaptations made to fit the specific problems of stroke patients and their families Finally, the construction of an Inventory of Goals is described.

Chapter two reports on miscellaneous innovations developed during the project. These include ways of using research clerks and secretaries as counselor aides and a discussion of the social interaction implications of providing patient transportation.

Research utilization is covered in Chapter three. In Chapter four, entitled "Discussion and Conclusions", the data is related to findings from other studies and general trends to be inferred from the study are suggested.

Chapter 5, "Summary and Implications", is a recapitulation in briefer form of the summary and implications appearing at the end of the relevant chapters.

A combined author-subject index for Volume II is included. An Appendix contains more detail data on MADLI ratings, a methodological note on the reliability of the instruments and additional excerpts from a content analysis of the counseling records.

CHAPTER 1

INSTRUMENTATION

Several instruments were developed or adapted to measure patient attitudes and activities. These included a classification system for avocational activities, an activities of daily living scale, an attitude toward disability inventory, an inventory of goals and two inventories of perception of roles. Each of these will be described in this chapter.

A. Avocational Activities: Inventory, File and Descriptions

In order to have a systematic method of classifying and coding activities, a classification system modeled after the Dictionary of Occupational Titles* was developed. This includes the following ten major areas:

0. Games
1. Sports
2. Nature Activities
3. Collection Activities
4. Craft Activities
5. Art and Music Activities (Performing)
6. Educational and Cultural Activities
7. Volunteer Activities
8. Organizations
9. Social Relationships

These are further subdivided into 2 and 3 digit level classification for a total of 900 three digit entries. The "Avocational Activities Inventory" has been published and disseminated as Report No. 5 in the Milwaukee Media for Rehabilitation Research Reports, June 1968. **

A community resource file comprised of information about avocational activities in the Milwaukee community as well as general information about avocational activities was developed. This is maintained in folders in a vertical file with file folders numbered in accordance with the Avocational Activities Inventory classification code. After a year, we inventoried the file in order to show the contents. **

An article in the Journal of Health, Physical Education and Recreation entitled "A Model for Avocational Counseling" by the Project Director discusses the need for avocational counseling, how to go about it and how the Avocational Activities Inventory and the Avocational Activities File may be used as supporting technical instruments. Reprints are available upon request. **

A continuation of this work is being carried on under a grant from the U. S. Office of Education to write descriptions of the 900 classified and coded avocational activities.*** The writeups are designed to give the disabled person and his counselor information useful in making decisions as to whether

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* U.S. Department of Labor, Dictionary of Occupational Titles, Washington, D.C., U.S. Government Printing Office, 1965.

** Copies of these may be obtained by writing: Research Department, Curative Workshop of Milwaukee, 750 North 18th Street, Milwaukee, Wis., 53233.

***Avocational Activities Descriptions, Project No. 1-E-055, 6/1/71-5/31/72, U.S. Office of Education.

an activity is suitable considering the limitations of the client. Particular attention is being paid to activities suitable for the severely disabled. A chart of impairments has been developed in order to rate each activity according to whether or not a person with a given impairment can perform the activity. We hope to show how the dimensions of very simple activities can be expanded to make the activity more interesting for those whose disability limits the types of activities in which they may participate.

Great emphasis is being placed on the degree to which the avocational activity contributes to social interaction. Avocational activities could provide a base for a developing network of friends and acquaintances, and in this way serve to bring severely disabled individuals back into contact with others. In our opinion this would be more significant than any other possible outcome of the activity, especially for the homebound or severely disabled. Ways to utilize activities in this way are being explored. *

B. Milwaukee Activities of Daily Living Inventory (MADLI)

A second needed measuring device was an activities of daily living scale. A search of relevant professional literature since 1951 unearthed twelve such scales and a critical review of these was published (Bruett and Overs, 1969 - general). In order to provide a scale better adapted to the type of decisions which must be made by stroke patients and their families a new scale was constructed. It is entitled the Milwaukee Activities of Daily Living Inventory (MADLI). This was developed by the CVA Program Coordinator, the Supervisor of Occupational Therapy, a Research Assistant and the authors. Many items from other scales were adapted for use in the MADLI.

The MADLI presents a profile of a patient's ability to perform nine activities of daily living using a non-averaged, non-totaled,pass-fail type of scoring for each item.

This seems preferable for the types of decision which a family must make concerning the care of the patient. Families must decide how to provide the minimum degree of safety for the patient which is consistent with the physical and psychological condition of the patient, meets the normative standards of the community, and does not exceed their financial limitations. The type of decision reached could vary according to the patient's ability on any one item on the scale. Thus a total score would not be useful. For example, if a patient could not walk unassisted it would not matter if he was rated as independent on every other item. He could not safely be left alone in the house because of the danger of fire.

The theoretical orientation to the scale, and the instructions to the raters, which follow, present these concepts in more detail.

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* If you wish to receive a notice of the availability of this publication when issued, write Research Department, Curative Workshop of Milwaukee, 750 North 18th Street, Milwaukee, Wisconsin, 53233.

Theoretical Orientation

The Milwaukee Activities of Daily Living Inventory (MADLI) presents information about severely disabled patients to the patient's family in a form useful for making decisions about the type of assistance needed by the patient. Three major dimensions are pertinent in this decision making process: the physical, the psychological, and the social.

Attempts to measure the remaining physical abilities of the patient have been reported in at least twelve published scales. The usefulness of this type of measure should need no elaboration.

The psychological reactions of the situation include the patient's attitude toward the person helping him and the assistant's attitude toward the patient. Some patients become so emotionally dependent upon the care of one particular assistant that receiving help from other assistants is not fully acceptable to them. On the other hand, if the assistant is inexperienced, lacks self-confidence, or is basically unconcerned about the patient's welfare, this will be quickly sensed by the patient. The family's selection of an assistant must take these factors into consideration.

The social aspects of the situation include the expectations of the community of which the family is a part. The decision reached must be within the acceptable range of normative behavior. The chief concern of the family is to provide the patient with the degree of care, particularly in respect to his physical safety, which will meet the expectations of the community. For instance, a family would be severely criticized by the community if a helpless disabled person was burned in a fire because he had been left without assistance. On the other hand, to provide 24 hour care, if it is not absolutely essential, ties up the time of other family members or becomes a major financial drain on the family if assistants are hired to perform this function.

It is our belief that the psychological and social factors, which have to be considered, are important in the decision the family has to make and that a scale should include these if it is to be of maximum use to the family. If these factors are not built into the scale, the family of the patient has to translate the findings of the clinically orientated ADL inventories in order to use them in the decision making required to care for the patient.

The fact that the patient requires the assistance of at least one other person creates a social interaction situation with its own dynamic processes which are apart from the physical needs of the patient. The family cannot avoid this social interaction when making its decision about the type of care, to be provided for the patient.

By concentrating on the physical aspects alone, the previous ADL scales have left the family with the problem of implementing the information about the patients physical condition within the limits of the social situation. In contrast, the MADLI attempts to incorporate the psychological and social dimensions within the scale itself. It does this by specifying the type of assistance required by the patient so that the rater is forced to think of the psychological and social role which the assistant will play.

The person who has the major full time responsibility for the patient's welfare plays a substantially different role both psychologically and socially from that played by the intermittent, occasional and part time helper. From a psycho-

logical viewpoint, the patient views these two types of assistants differently and the assistants, carrying out these roles, view themselves and their roles differently.

The community also views these roles differently and has definite expectations in respect to the age, sex and degree of blood relationship appropriate to each role. For instance, while it might be considered appropriate for a 16 year old girl to prepare lunch for a severely disabled middle aged male, for her to provide unsupervised live-in total care, would be unacceptable,in many communities, unless she were his daughter or granddaughter.

The family then is faced with a decision as to how much and what kind of assistance must be provided the patient. The decision reached must take into account the combined physical, psychological and social implications involved in such a decision.

(evaluator) (date) (patient)

MILWAUKEE ACTIVITIES OF DAILY LIVING INVENTORY

Instructions to Raters

The Milwaukee Activities of Daily Living Inventory (MADLI) is constructed to appraise and express a patient's profile of remaining abilities in terms of his home living problems. It is designed to describe his needs in a way useful to both the family and patient in making decisions about the degree of assistance the patient requires to live at home.

You, as a rater, are asked to judge whether the patient is independent, semi-dependent or dependent in each of nine activities. Please base your judgment upon your observations of the patient. The three levels of patient functioning are described below:

Level 3 Independent (no assistant required): patient can perform activity without an assistant, but may rely on a mechanical device. The patient performs well enough to safely carry on activity on his own without supervision or assistance.

Level 2 Semi-Dependent (assistant required): patient needs the occasional, partial or intermittant assistance of a less experienced assistant. This assistant need not fully meet the criteria outlined in level 1. As a friend, neighbor, acquaintance or employee, the less experienced assistant must be capable of supplying the supplementary aid which the patient requires for that specific activity. This aid need not be fully "professionalized" in nature. This assistant may not be seen as fulfilling the level 1 role.

Level 1 Dependent (assistant required): patient is consistently unable to complete the activity by himself. The assistant must be physically, emotionally, and intellectually able to meet the total needs of the patient in the category being rated. Such a person must be acceptable to the patient as someone who has close personal contact with him. This relationship between the patient and client must meet societal expectations of what this relationship should be. The assistant must have the self-confidence to feel adequate and comfortable with his responsibilities.

Each activity is scored separately, and a profile of the patient's ability is obtained. There is no effort to add these into a total score.

Time limits for performance of an activity are set for the rating of independent (level 3) on items 4,5 and 9. The patient is required to be able to perform the activity in five minutes, the maximum time estimated necessary to leave a house in case of fire. For the other items the rater should use his own judgment as to a reasonable length of time for performance in a given activity.

Research Department
Curative Workshop of Milw.
2537-P Form #4
May 1968

Mechanical assistance is not given a separate rating since the intention is to rate such devices within the above scale according to the efficiency with which they are used.

If a patient is unable to perform an activity because of memory loss or confused thinking, he is considered to need an assistant in the same manner as if he needed physical assistance.

If a patient fluctuates in the level of assistant needed, he will ordinarily be rated at his lowest level.

1. In eating, he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

   The patient is independent if he can feed himself other than having his food placed within reach. He is not required to be able to cut meat but he must be able to use salt and sugar. He may use a straw when drinking. If he needs an assistive device, he must be able to put it on. The patient is semi-dependent if he uses an assistive device that he cannot put on by himself, or if he needs help with sugar or salt. If, because of psychological dependency, the patient will only eat when assisted by one particular person, he is at level 1 regardless of physical ability.

2. In transferring in and out of bed or chair (wheelchair included), he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

   The independent patient (in a wheelchair) can approach the bed (in his wheelchair, lock the brakes, lift the foot rest), get in to the bed, lie down, sit up, (change the position of the chair if necessary, and return to it). The patient is not expected to get on and off a bed too high (for his wheelchair or) for his height. The patient is semi-dependent if he performs the activity with minimal help or needs supervision for safety. If because of psychological dependency, the patient will carry out these activities only when encouraged by one particular assistant, he is at level 1 regardless of physical ability.

3. In dressing (including underclothes and outer garments, using fasteners) he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

   To be independent the patient must be able to put on and take off clothes, fasten most fasteners and if shoe laces are used, to tie them. He must be able to dress himself appropriately to appear in public but what is appropriate will vary according to the social situation. Inability to button one sleeve and similar inconsequential items will not prevent a rating of independent. The patient may need to use special clothing, such as dresses that open

down the front. The patient is scored as semi-dependent when he needs minimal physical help or minimal verbal instruction. If the person needs constant verbal assistance, then he is rated as dependent. Women need not put on a girdle unless this is perscribed. If the patient needs help but will only accept it from one particular assistant he is dependent (level 1).

4. While walking on a level surface, he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

The patient who can walk at least 25 yards without help or supervision is considered independent. He may wear braces or prosthesis and use crutches, canes or a walker. He must lock and unlock braces, stand up and sit down, get the mechanical aids into position for use and dispose of them when he sits, and open doors. (Putting on and off of braces is scored under item 8.) The patient is scored as semi-dependent if he needs minimal help or supervision. He is dependent if he cannot walk with minimal help or walks only in the parallel bars.

A patient should not receive a lower rating than he otherwise would if he uses equipment such as canes, crutches, pick-up walkers, etc., except that in order to receive an independent rating he must be able to pick up and position equipment with no assistance.

To be judged independent (level 3) he must be able to make his way out of an average house with no stairs (but including opening the door) within five minutes, just as he would to save himself in case of fire.

If the patient needs help but will accept it from only one particular assistant he is dependent (level 1).

5. In propelling a wheelchair he (she) is: (This activity is scored only when the patient uses a wheelchair.)
   3) Independent
   2) Semi-dependent
   1) Dependent
   Not Applicable

He is independent if he can propel the chair for at least 25 yards, is able to go around corners, can maneuver the chair to a table, and can open a door (hinge type). He must be able to make his way out of an average house with no stairs (but including opening the door) within five minutes, just as he would to save himself in case of fire.

6. In using the dial telephone he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

A patient is independent if he can use a dial telephone without help. The criterion for this is whether or not the patient would be able to call someone

for aid in case of an emergency. If he needs someone to dial the phone for him, to hold it for him, or to read the number or show him where to look for the number, he requires an assistant and is scored as semi-dependent. If he will use the telephone only when helped or encouraged by one particular assistant he is dependent (level 1).

7. In using the push button telephone he (she) is: (This activity is scored only when the patient is unable to use the dial telephone.)
   3) Independent
   2) Semi-dependent
   1) Dependent

   A patient is independent if he can use a push button telephone without help. The criterion for this is whether or not the patient would be able to call someone for aid in case of an emergency. If he needs someone to operate the phone for him, to hold it for him, or to read the number or show him where to look for the number, he requires an assistant and is scored as semi-dependent. If he will use the telephone only when helped or encouraged by one particular assistant he is dependent (level 1).

8. In putting on leg braces he (she) is: (This activity is not scored if the patient does not use adaptive equipment.)
   3) Independent
   2) Semi-dependent
   1) Dependent
   Not Applicable

   No leg braces are excused from the item. To be independent the patient must be able to put on any leg braces which he usually wears. If the patient needs help but will only accept it from one particular assistant he is dependent (level 1). Upper extremity devices are excluded.

9. In ascending and descending the stairs he (she) is:
   3) Independent
   2) Semi-dependent
   1) Dependent

   The patient who can go up or down at least one flight of stairs without help or supervision is scored as independent. He may use handrails, canes, or crutches if needed. It he needs a cane or crutches for walking on level ground, he must carry them with him as he ascends and descends the stairs. The patient is semi-dependent if he needs minimal help. He is scored as dependent (level 1) if he needs to be carried up and down one flight of stairs. To be judged independent (level 3) he must be able to climb or descend a flight of stairs within five minutes, just as he would to save himself in case of fire. It the patient needs help but will accept it from only one particular assistant he is dependent (level 1).

Research Department
Curative Workshop of Milw.
Form # 14b
2537 P

Date_____
Scored by___

P NP
H
W

Case #_____
Name_____

Follow-up_____
Discharge_____
Admission_____

MILWAUKEE ACTIVITIES OF DAILY LIVING INVENTORY (MADLI)
Short Form
(see Instructions to Raters for complete description of scoring procedure)

Items			
1-eating	Independent	Semi-dependent	Dependent
2-transfering	Independent	Semi-dependent	Dependent
3-dressing	Independent	Semi-dependent	Dependent
4-walking	Independent	Semi-dependent	Dependent
5-wheelchair	Independent	Semi-dependent	Dependent
6-dial phone	Independent	Semi-dependent	Dependent
7-push-button phone	Independent	Semi-dependent	Dependent
8-leg braces	Independent	Semi-dependent	Dependent
9-stairs	Independent	Semi-dependent	Dependent

Inventories of Patient and Spouse Attitudes

As an additional approach to measurement, three inventories of patient and spouse attitudes were adapted for the Project. These measurements were useful both for evaluating the effectiveness of the demonstration and for plotting general attitudinal trends in this sample of patients and their spouses.

An analysis of individual items also turned out to be useful in conjunction with counseling reports in better understanding individual patients and the relationships existing between particular patient-spouse dyads. Copies of all of these inventories, except the original copywrited scales of other authors, are available upon request.

The inventories were pretested on twelve stroke patients and their spouses already in the rehabilitation program prior to the data collection period.

Our policy was to use or adapt existing instruments whenever possible rather than create our own. Ideally, this saves time, utilizes existing standardization norms and makes results comparable from one study to another. In practice, we found that more adaptations had to be made than we anticipated and these involved complex theoretical questions of psychological set and word meaning. We were also faced with the practical problem of shortening the instruments sufficiently to be within the fatigue and motivational limits of an elderly and severely disabled population.

There were many difficulties in administering these inventories. Approximately half of the patients were aphasic. The administration of inventories frequently had to be done while patients were waiting for therapy or waiting for transportation home; consequently, interruptions often occurred before the inventories were finally completed.

Because this was an older population with relatively limited formal education, the patients and their spouses had little insight into the usefulness of these instruments. They had reading difficulties and tired easily. In our effort to explore patient and spouse self concepts, roles and goals, extensive lists of questions were asked. What might have been an easy and interesting intellectual task for college sophomore psychology students was hard work for a group of elderly, severely disabled, eighth-grade graduates.

We will now procede to describe the attitude inventories used and the adaptations we made to them.

C. Suinn-Feldman Rehabilitation Self-Description Scale *

The Suinn-Feldman Rehabilitation Self-Description Scale was administered. This was an eighty-two item, five-step Likert type questionnaire. Twenty-five questions (30.5%) were related to disability. The remaining fifty-seven questions (69.5%) were general personality inventory type items.

*This scale is copywrited and was used with the permission of the author. Dr. Richard M. Suinn, Ph.D., Dept. of Psychology, Colorado State University, Fort Collins, Colorado 80521, may be contacted with respect to its use.

SUINN-FELDMAN REHABILITATION SELF-DESCRIPTION SCALE

	P	NP
H		
W		

Research Department
Curative Workshop of Milw.
Form #5-C (2537-P)
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DIRECTIONS: This questionnaire will help the staff to better understand you. It involves a number of statements which people use to describe themselves and their beliefs or attitudes. If you strongly agree with the statement, circle "SA", if you agree with it, circle "A"; if you disagree with it, circle "D"; if you strongly disagree, circle "SD"; and if you don't know, circle "?". Try to avoid using the "?" type of answer if you can.

STATEMENT	YOUR ANSWER (1) SA	(2) A	(3) ?	(4) D	(5) SD
1. There are so many things I want to do that I often can't decide what to do first.					
2. I get restless unless I keep busy.	SA	A	?	D	SD
3. The important thing to do if you are disabled is to learn to ignore your disability.	SA	A	?	D	SD
4. I enjoy peace and quiet.	SA	A	?	D	SD
5. The worst thing about the treatment is that it seems so slow.	SA	A	?	D	SD
6. I think that life without competition would be very boring.	SA	A	?	D	SD
7. I enjoy doing things more than watching others do things.	SA	A	?	D	SD
8. I'd give up if there weren't so many people helping me.	SA	A	?	D	SD
9. I feel happiest when I accomplish something that I can point to.	SA	A	?	D	SD
10. I believe a person should try his hardest to advance in whatever he does in life.	SA	A	?	D	SD
11. There is no point in trying to fight fate; you might just as well accept life as it comes.	SA	A	?	D	SD
12. I don't seem to be able to accept the problems that come my way as well as other people seem to be able to accept their problems.	SA	A	?	D	SD
13. When someone makes me angry, I usually try to avoid that person in the future.	SA	A	?D	D	SD
14. Other people probably know me better than I know myself.	SA	A	?	D	SD

form #5-C (2537-P)

STATEMENT	YOUR ANSWER (1) SA	(2) A	(3) ?	(4) D	(5) SD
15. I can't sit still for long.					
16. This may seem silly, but I think that being disabled can have its advantages.	SA	A	?	D	SD
17. I think that my condition is really too bad for anyone to expect any real gains from treatment.	SA	A	?	D	SD
18. My greatest desire while in the hospital is to leave and get back to work and a normal life.	SA	A	?	D	SD
19. I know now that I need help from others.	SA	A	?	D	SD
20. I try at all times to be nice to people.	SA	A	?	D	SD
21. I am concerned about having others like me.	SA	A	?	D	SD
22. I tend to dominate others without meaning to.	SA	A	?	D	SD
23. I am very sure of myself.	SA	A	?	D	SD
24. I really dislike having to rely upon others for anything.	SA	A	?	D	SD
25. When I get upset, I look for someone to help me.	SA	A	?	D	SD
25. I sometimes think that someone else was responsible for the condition I'm in.	SA	A	?	D	SD
27. I frequently think about the ways in which the disability could have been avoided.	SA	A	?	D	SD
28. All my life I have tried to master things.	SA	A	?	D	SD
29. It takes me a long time to get over angry or hurt feelings.	SA	A	?	D	SD
30. Being disabled forces a person to change many goals drastically.	SA	A	?	D	SD
31. A person who is disabled is very different from other people.	SA	A	?	D	SD
32. I do enjoy it when others show that they can understand me and the way I feel.	SA	A	?	D	SD
33. When a person irritates me, I immediately let him know it.	SA	A	?	D	SD
34. I think that other people are generally more capable in doing even those things which I'm supposed to be good at.	SA	A	?	D	SD

form #5-C (2537-P)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
35. I enjoy being in places with many people around; I'm sociable.	SA	A	?	D	SD
36. I am a timid person.	SA	A	?	D	SD
37. I believe that there are many things which I could explain to the doctors regarding my condition.	SA	A	?	D	SD
38. I am very anxious to cooperate with the treatment program.	SA	A	?	D	SD
39. I am an extremely independent person, maybe too much so.	SA	A	?	D	SD
40. My temper often gets out of hand.	SA	A	?	D	SD
41. I enjoy just sitting and doing nothing for long periods of time.	SA	A	?	D	SD
42. I'm secretly certain that I will be as good as new before long.	SA	A	?	D	SD
43. I know that treatment should help me but I also think that I could probably get along without it.	SA	A	?	D	SD
44. When I get upset I do something about it even though it isn't always the right thing.	SA	A	?	D	SD
45. I secretly do enjoy the attention and reassurances others give me.	SA	A	?	D	SD
46. I think I know most of my faults and my good points better than anyone else does.	SA	A	?	D	SD
47. When someone does or says something that hurts my feelings, I tend to keep it to myself.	SA	A	?	D	SD
48. I know that people don't understand what it's like to be disabled.	SA	A	?	D	SD
49. I am determined to prove to others that I can still do the same things I did before.	SA	A	?	D	SD
50. I am a person with a great many things to do in life, but very little time to do them in.	SA	A	?	D	SD
51. I always seem to be in a rush.	SA	A	?	D	SD
52. I guess I'm not very interested in life or anything anymore.	SA	A	?	D	SD

form #5-C (2537-P)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
53. I enjoy participating in games and social activities where my skills are matched against those of other people.	SA	A	?	D	SD
54. My self-esteem has been harmed by my being disabled.	SA	A	?	D	SD
55. I think people should be educated in how to behave towards a disabled person.	SA	A	?	D	SD
56. I've adapted fine to being disabled, but my friends can't seem to accept my disability.	SA	A	?	D	SD
57. People are often uncomfortable at being in a room with a disabled person.	SA	A	?	D	SD
58. I think that one of the most important things in life is remaining mentally and physically alert.	SA	A	?	D	SD
59. I do not enjoy following a routine.	SA	A	?	D	SD
60. I sometimes feel bad about being physically different from others.	SA	A	?	D	SD
61. If I had magical powers, the first thing I would do is change my physical condition.	SA	A	?	D	SD
62. If I had magical powers the first thing I would do is change my personality.	SA	A	?	D	SD
63. If I had magical powers, the first thing I would do is change my intelligence.	SA	A	?	D	SD
64. I find it difficult to sleep nights without the help of a sleeping pill.	SA	A	?	D	SD
65. The days seem to pass slowly for me.	SA	A	?	D	SD
66. The thing that really bothers me a lot is the feeling of being helpless.	SA	A	?	D	SD
67. People are basically very kind and helpful.	SA	A	?	D	SD
68. I think it is very important for me to try to be thoughtful and helpful towards others.	SA	A	?	D	SD
69. It has become more and more difficult for me to retain my interest in things I used to find interesting.	SA	A	?	D	SD
70. I am a person who has always been able to deal with new situations.	SA	A	?	D	SD

form #5-C (2537-P)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
71. I enjoy a challenge, especially when it involves proving myself.	SA	A	?	D	SD
72. I have usually avoided unfamiliar places, or persons, or things.	SA	A	?	D	SD
73. If I have a problem to solve, I can usually find different ways of solving it without someone else's help.	SA	A	?	D	SD
74. When someone asks me to find out some information, I can usually do so without hesitation.	SA	A	?	D	SD
75. I usually like to avoid crowds; I'd much rather be alone.	SA	A	?	D	SD
76. I am a bold and daring person.	SA	A	?	D	SD
77. I feel there should be special laws created to provide the disabled with special privileges.	SA	A	?	D	SD
78. I think that the first thing people notice about me is my disability.	SA	A	?	D	SD
79. Often bodily or physical sensations take up most of my attention.	SA	A	?	D	SD
80. I am a determined person and I dislike being helped.	SA	A	?	D	SD
81. I am a determined person and I do not mind being helped.	SA	A	?	D	SD
82. This questionnaire is a waste of my time.	SA	A	?	D	SD

D. Description by Spouse Scale

A Description by Spouse Scale was constructed to parallel the Suinn-Feldman Rehabilitation Self-Description Scale. The Spouse Scale attempts to measure how the spouse perceives the patient and the degree to which the perception of the spouse agrees with that of the patient. There are two forms: one for a husband - patient, wife non-patient combination; the other for a wife-patient, husband non-patient combination. The idea was suggested by Dr. Nathan Hurvitz's Marital Roles Inventory and some of his scoring procedures are applicable.

We attempted to keep the wording in the Spouse Scale closely parallel to that in the Self-Description Scale. Because of response set difficulties, we divided the items into two groups, each eliciting a different response set. We prefaced each group of items with a different set of instructions clearly indicating the desired response set. Thus, in the initial thirteen item group the spouse is asked to describe the patient's behvaior. In the second group, which includes the remaining items, the spouse is asked to describe the patient's beliefs and/or attitudes.

The basis for making the distinction between the two types of items was the need to determine whether information about the patient was derived by direct observation of behavior including overt communication, or whether information about the patient's beliefs and attitudes was inferred from the patient's statements.

As an additional aid in making the distinction between the required type of response set, in some of the statements we found an analysis of the verb helpful. Verbs expressing movement or overt communication suggested that behavior would be observed and enabled the item to be assigned to the group for which a description of behavior response set is appropriate. A sample item is number two (Suinn-Feldman number thirteen), "When someone makes him angry he usually tries to avoid that person in the future." Verbs expressing the internal state of the patient tended to be assigned to the group for which a description of beliefs and/or attitudes is appropriate. A sample is item thirty-six (Suinn-Feldman number forty-two), "He is secretly certain that he will be as good as new before long."

After the classification system was constructed, three judges were able to assign items to their respective groups with high agreement, and the few cases of non-agreement were readily resolved through discussion.

Using the Suinn-Feldman Rehabilitation Self-Description Scale and the Description by Spouse Scale in combination, it was possible to compute the degree to which the spouse's perception of the patient agreed with the patient's perception of himself.

The Description by Spouse Scale is presented on the pages immediately following. The number in parenthesis after the statement refers to the comparable statement on the Suinn-Feldman Rehabilitation Self-Description Scale.

NAME:_____ DATE:_____

DESCRIPTION BY SPOUSE SCALE

Research Department
Curative Workshop of Milw.
Form #5-a (beh.) (1/25/68)
2537 P

	P	NP
H	x	
W		x

DIRECTIONS: People have used these statements to describe their husbands' behavior. If you strongly agree that the statement represents your husband's behavior, circle "SA;" if you agree, circle "A;" if you disagree, circle "D;" if you strongly disagree, circle "SD;" and if you don't know, circle "?." Try to avoid using the "?" type of answer if you can.

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
1. He gets restless unless he keeps busy. (2)	SA	A	?	D	SD
2. When someone makes him angry, he usually tries to avoid that person in the future. (13)	SA	A	?	D	SD
3. He can't sit still for long. (15)	SA	A	?	D	SD
4. He tends to dominate others without meaning to. (22)	SA	A	?	D	SD
5. When a person irritates him, he immediately lets him know it. (33)	SA	A	?	D	SD
6. His temper often gets out of hand. (40)	SA	A	?	D	SD
7. When he gets upset he does something about it even though it isn't always the right thing. (44)	SA	A	?	D	SD
8. He enjoys participating in games and social activities where his skills are matched against those of other people. (53)	SA	A	?	D	SD
9. He finds it difficult to sleep nights without the help of a sleeping pill. (64)	SA	A	?	D	SD
10. He is a person who has always been able to deal with new situations. (70)	SA	A	?	D	SD
11. He has usually avoided unfamiliar places, or persons, or things. (72)	SA	A	?	D	SD
12. When someone asks him to find out some information, he can usually do so without hesitation. (74)	SA	A	?	D	SD
13. He is a bold and daring person. (76)	SA	A	?	D	SD

NAME:_____ DATE:_____

DESCRIPTION BY SPOUSE SCALE

Research Department
Curative Workshop of Milw.
Form #5-a (att.) (1/25/68)
2537 P

	P	NP
H	x	
W		x

DIRECTIONS: People have used these statements to describe their husband's beliefs or attitudes. If you strongly agree that the statement represents your husband's beliefs or attitudes, circle "SA;" if you agree, circle "A;" if you disagree, circle "D;" if you strongly disagree, circle "SD;" and if you don't know, circle "?." Try to avoid using the "?" type of answer if vou can.

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
1. There are so many things he wants to do that he often can't decide what to do first. (1)	SA	A	?	D	SD
2. He believes that the important thing to do if you are disabled is to learn to ignore your disability. (3)	SA	A	?	D	SD
3. He enjoys peace and quiet. (4)	SA	A	?	D	SD
4. He feels that the worst thing about the treatment is that it seems so slow. (5)	SA	A	?	D	SD
5. He thinks that life without competition would be very boring. (6)	SA	A	?	D	SD
6. He enjoys doing things more than watching others do things. (7)	SA	A	?	D	SD
7. He'd give up if there weren't so many people helping him. (8)	SA	A	?	D	SD
8. He feels happiest when he accomplishes something that he can point to. (9)	SA	A	?	D	SD
9. He believes a person should try his hardest to advance in whatever he does in life. (10)	SA	A	?	D	SD
10. He feels that there is no point in trying to fight fate; you might just as well accept life as it comes. (11)	SA	A	?	D	SD

Form #5-a (att.)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
11. He doesn't seem to be able to accept the problems that come his way as well as other people seem to be able to accept their problems. (12)	SA	A	?	D	SD
12. He believes that other people probably know him better than he knows himself. (14)	SA	A	?	D	SD
13. This may seem silly, but he thinks that being disabled can have its advantages. (16)	SA	A	?	D	SD
14. He thinks that his condition is really too bad for anyone to expect any real gains from treatment. (17)	SA	A	?	D	SD
15. His greatest desire while in the hospital is to leave and get back to work and a normal life.(18)	SA	A	?	D	SD
16. He knows now that he needs help from others. (19)	SA	A	?	D	SD
17. He tries at all times to be nice to people. (20)	SA	A	?	D	SD
18. He is concerned about having others like him. (21)	SA	A	?	D	SD
19. He is very sure of himself. (23)	SA	A	?	D	SD
20. He really dislikes having to rely upon others for anything. (24)	SA	A	?	D	SD
21. When he gets upset, he looks for someone to help him. (25)	SA	A	?	D	SD
22. He sometimes thinks that someone else was responsible for the condition he's in. (26)	SA	A	?	D	SD
23. He frequently thinks about ways in which the disability could have been avoided. (27)	SA	A	?	D	SD
24. All his life he has tried to master things. (28)	SA	A	?	D	SD
25. It takes him a long time to get over angry or hurt feelings. (29)	SA	A	?	D	SD

form #5-a (att.)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
26. He thinks that being disabled forces a person to change many goals drastically. (30)	SA	A	?	D	SD
27 He believes that a person who is disabled is very different from other people. (31)	SA	A	?	D	SD
28. He does enjoy it when others show that they can understand him and the way he feels. (32)	SA	A	?	D	SD
29. He thinks that other people are generally more capable in doing even those things which he's supposed to be good at. (34)	SA	A	?	D	SD
30. He enjoys being in places with many people around; he's sociable. (35)	SA	A	?	D	SD
31. He is a timid person. (36)	SA	A	?	D	SD
32. He believes that there are many things which he could explain to the doctors regarding his condition. (37)	SA	A	?	D	SD
33. He is very anxious to cooperate with the treatment program. (38)	SA	A	?	D	SD
34. He is an extremely independent person, maybe too much so. (39)	SA	A	?	D	SD
35. He enjoys just sitting and doing nothing for long periods of time. (41)	SA	A	?	D	SD
36. He is secretly certain that he will be as good as new before long. (42)	SA	A	?	D	SD
37. He knows that treatment should help him but he also thinks that he could get along without it. (43)	SA	A	?	D	SD
38. He secretly does enjoy the attention and reassurances others give him. (45)	SA	A	?	D	SD
39. He thinks he knows most of his faults and his good points better than anyone else does. (46)	SA	A	?	D	SD
40. When someone does or says something that hurts his feelings, he tends to keep it to himself. (47)	SA	A	?	D	SD

form #5-a (att.)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
41. He knows that people don't understand what it's like to be disabled. (48)	SA	A	?	D	SD
42. He is determined to prove to others that he can still do the same things he did before. (49)	SA	A	?	D	SD
43. He is a person with a great many things to do in life, but very little time to do them in. (50)	SA	A	?	D	SD
44. He always seems to be in a rush. (51)	SA	A	?	D	SD
45. He's not very interested in life or anything anymore. (52)	SA	A	?	D	SD
46. His self-esteem has been harmed by his being disabled. (54)	SA	A	?	D	SD
47. He thinks people should be educated in how to behave towards a disabled person. (55)	SA	A	?	D	SD
48. He's adapted fine to being disabled, but his friends can't seem to accept his disability. (56)	SA	A	?	D	SD
49. He feels that people are often uncomfortable at being in a room with a disabled person. (57)	SA	A	?	D	SD
50. He thinks that one of the most important things in life is remaining mentally and physically alert. (58)	SA	A	?	D	SD
51. He does not enjoy following a routine. (59)	SA	A	?	D	SD
52. He sometimes feels bad about being physically different from others. (60)	SA	A	?	D	SD
53. If he had magical powers, the first thing he would do is change his physical condition. (61)	SA	A	?	D	SD
54. If he had magical powers, the first thing he would do is change his personality. ((62)	SA	A	?	D	SD
55. If he had magical powers, the first thing he would do is change his intelligence. (63)	SA	A	?	D	SD

Form #5-a (att.)

STATEMENT	YOUR ANSWER (1)	(2)	(3)	(4)	(5)
56. The days seem to pass slowly for him. (65)	SA	A	?	D	SD
57. The thing that really bothers him a lot is the feeling of being helpless. (66)	SA	A	?	D	SD
58. He feels that people are basically very kind and helpful. (67)	SA	A	?	D	SD
59. He thinks it is very important for him to try to be thoughtful and helpful towards others. (68)	SA	A	?	D	SD
60. It has become more and more difficult for him to retain his interest in things he used to find interesting. (69)	SA	A	?	D	SD
61. He enjoys a challenge, especially when it involves proving himself. (71)	SA	A	?	D	SD
62. If he has a problem to solve, he can usually find different ways for solving it without someone else's help. (73)	SA	A	?	D	SD
63. He usually likes to avoid crowds; he would much rather be alone. (75)	SA	A	?	D	SD
64. He feels there should be special laws created to provide the disabled with special privileges. (77)	SA	A	?	D	SD
65. He thinks that the first thing people notice about him is his disability. (78)	SA	A	?	D	SD
66. Often bodily or physical sensations take up most of his attention. (79)	SA	A	?	D	SD
67. He is a determined person and he dislikes being helped. (80)	SA	A	?	D	SD
68. He is a determined person and he does not mind being helped. (81)	SA	A	?	D	SD
69. He would think that this questionnaire is a waste of time. (82)	SA	A	?	D	SD

Short Forms of the Suinn-Feldman Rehabilitation Self-Description Scale and of the Description by Spouse Scale

After analyzing the responses on sixty-seven completed Suinn-Feldman Rehabilitation Self-Description Scales and fifty-one Description by Spouse Scales, each of the scales was shortened from eighty-two to twenty-two questions. The items which had been separated into behavior vs. beliefs or attitudes were recombined into a single inventory. The five-step Likert type answers were reduced to an agree or disagree dichotomy.

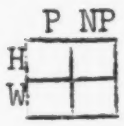
The twenty-two items retained included ten, which preliminary analysis by Drs. Suinn and Feldman on their own population found to be predictive of successful rehabilitation, and twelve which seemed to discriminate between patients and spouses in our samples.

The shortened form of the Suinn-Feldman Rehabilitation Self-Description Scale was renamed the Suinn-Feldman Self-Description and the shortened form of the Description by Spouse Scale was renamed the Suinn-Feldman Spouse Description.

Both shortened forms are presented on the four following pages. The numbers in parentheses at the end of the statements refer to the number that item would be on the original Suinn-Feldman Rehabilitation Self-Description Scale.

SUINN-FELDMAN SELF-DESCRIPTION

Research Department
Curative Workshop of Milw.
Form # 5-C (2537-P) Revised
Copyright 1966 by R.M. Suinn and D.J. Feldman



DIRECTIONS: This questionnaire will help us understand you and other stroke patients. It involves a number of statements which people sometimes use to describe themselves and their beliefs or attitudes. If you agree with the statement circle AGREE. If you disagree with the statement circle DISAGREE.

STATEMENT	YOUR ANSWER	
1. I am very sure of myself (23).	AGREE	DISAGREE
2. There is no point in trying to fight fate; you might just as well accept life as it comes (11).	AGREE	DISAGREE
3. I know that therapy should have helped me but I also think I could probably have gotten along without it (43).	AGREE	DISAGREE
4. People are often uncomfortable at being in a room with a disabled person (57).	AGREE	DISAGREE
5. My self-esteem has been harmed by my being disabled (54).	AGREE	DISAGREE
6. I get restless unless I keep busy (2).	AGREE	DISAGREE
7. This may seem silly, but I think that being disabled can have its advantages (16).	AGREE	DISAGREE
8. I sometimes think that someone else was responsible for the condition I'm in (26).	AGREE	DISAGREE
9. I don't seem able to accept my problems as well as other people seem able to accept their problems (12).	AGREE	DISAGREE
10. I think that my condition is really too bad for anyone to expect any real gains from therapy (17).	AGREE	DISAGREE
11. The days seem to pass slowly for me (65).	AGREE	DISAGREE

Form 5-C (Cont'd)

12. I'm secretly certain that I will be as good as new before long (42). AGREE DISAGREE

13. I think that the first thing people notice about me is my disability (78). AGREE DISAGREE

14. I'd give up if there weren't so many people helping me (8). AGREE DISAGREE

15. Often bodily or physical sensations take up most of my attention (79). AGREE DISAGREE

16. I find it difficult to sleep nights without the help of a sleeping pill (64). AGREE DISAGREE

17 It takes me a long time to get over angry or hurt feelings (29). AGREE DISAGREE

18. I enjoy just sitting and doing nothing for long periods of time (41). AGREE DISAGREE

19. It has become more and more difficult for me to retain my interest in things I used to find interesting (69). AGREE DISAGREE

20. I guess I'm not very interested in life or anything anymore (52). AGREE DISAGREE

21. A person who is disabled is very different from other people (31). AGREE DISAGREE

22. The important thing to do if you are disabled is to learn to ignore your disability (3). AGREE DISAGREE

SUINN-FELDMAN SPOUSE DESCRIPTION

Research Department
Curative Workshop of Milw.
Form # 5-B (2537-P) Revised
Copyright 1966 by R.M. Suinn and D.J. Feldman

	P	NP
H		
W		

DIRECTIONS: This questionnaire will help us understand your spouse and other stroke patients. It involves a number of statements which people sometimes use to describe the behavior or beliefs of their spouse. If you agree with the statement circle AGREE. If you disagree with the statement circle DISAGREE.

STATEMENT	YOUR ANSWER	
1. He is very sure of himself (23).	AGREE	DISAGREE
2. He feels that there is no point in trying to fight fate; you might just as well accept life as it comes (11).	AGREE	DISAGREE
3. He knows that therapy should have helped him but he also thinks he could probably have gotten along without it (43).	AGREE	DISAGREE
4. He feels that people are often uncomfortable at being in a room with a disabled person (57).	AGREE	DISAGREE
5. His self-esteem has been harmed by his being disabled (54).	AGREE	DISAGREE
6. He gets restless unless he keeps busy (2).	AGREE	DISAGREE
7. This may seem silly, but he thinks that being disabled can have its advantages (16).	AGREE	DISAGREE
8. He sometimes thinks that someone else was responsible for the condition he's in (26).	AGREE	DISAGREE
9. He doesn't seem able to accept his problems as well as other people seem able to accept their problems (12).	AGREE	DISAGREE
10. He thinks that his condition is really too bad for anyone to expect any real gains from treatment (17).	AGREE	DISAGREE
11. The days seem to pass slowly for him.	AGREE	DISAGREE

Form # 5-B (Cont'd)

12.	He's secretly certain that he will be as good as new before long (42).	AGREE	DISAGREE
13.	He thinks that the first thing people notice about him is his disability (78).	AGREE	DISAGREE
14.	He'd give up if there weren't so many people helping him. (8)	AGREE	DISAGREE
15.	Often bodily or physical sensations take up most of his attention.	AGREE	DISAGREE
16.	He finds it difficult to sleep nights without the help of a sleeping pill (64).	AGREE	DISAGREE
17.	It takes him a long time to get over angry or hurt feelings (29).	AGREE	DISAGREE
18.	He enjoys just sitting and doing nothing for long periods of time (41).	AGREE	DISAGREE
19.	It has become more and more difficult for him to retain his interest in things he used to find interesting (69).	AGREE	DISAGREE
20.	He's not very interested in life or anything anymore (52).	AGRE	DISAGREE
21.	He feels that a person who is disabled is very different from other people (31).	AGREE	DISAGREE
22.	He feels that the important thing to do if you are disabled is to learn to ignore your disability (3).	AGREE	DISAGREE

E. Roles Inventory

The second attitude inventory used was the Marital Roles Inventory* developed by Nathan Hurvitz to measure perceived roles of patient and spouse. This consists of a four-way rank-ordering of nine role items. The husband ranks his own roles and those of his wife, and the wife ranks her own roles and those of her husband. "Four objective scores are obtained...each applicable to both the husband and wife". **

1. Index of Marital Strain: "Obtained by comparing one spouse's ranking of his own roles with the other spouse's ranking of these roles." **
2. Index of Deviation of Role Performances: "Score....obtained by comparing a spouse's ranking of the roles in his (her) role-set with the modal ranking of these roles by the normative group." **
3. Index of Deviation of Role Expectations: ".....Obtained by comparing a spouse's ranking of the roles in his (her) mate's role-set with modal ranking of these roles by the normative group." **
4. Corrected Index of Marital Strain: "....Obtained by adding the above three indexes." **

To save space we are presenting only two pages of the four page inventory. We have included the pages which inventory the husband's roles as perceived by the husband and the wife's roles as seen by the husband. The two additional pages, which we have omitted, inventory the husband's role as perceived by the wife and the wife's role as seen by the wife. On the omitted pages only the pronouns are changed, in order to be in accord with who is doing the perceiving.

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* This Inventory is copywrited by Nathan Hurvitz, Ph.D. and published by Western Psychological Services, Box 775, Beverly Hills, California.

** Hurvitz, Nathan, Ph.D., Marital Roles Inventory Manual, Beverly Hills; Western Psychological Services, 1961.

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Form #1--a
2537-P

MARITAL ROLES INVENTORY

Ranking Form H

	P	NP
H		
W		

by
Nathan Hurvitz, Ph.D.

published by
Western Psychological Services
W P S Publishers · Distributors · Consultants
Box 775, Beverly Hills, California

Name _____ Date _____

Below is a list of functions or roles of the American husband and father arranged in a random or haphazard order. Please read all the statements.

After you have read all the statements decide which one you carry out as your most important function or role in your family situation as it really is at the present time. Give it number 1. Then decide which one you carry out as your next most important function or role in your family situation as it really is at the present time. Give it number 2. Then number the other statements in the same way until you have a different number from 1 to 9 for each statement.

There is no correct order for these statements. One order may be as good or better than another order depending upon circumstances. Remember: Number these statements from 1 to 9 in the order of importance in which you actually carry out these roles in your family situation as it really is at the present time.

HUSBAND'S ROLES (H)

____I do my jobs around the house.

____I am a companion to my wife.

____I earn the living and support the family.

____I do my wife's work around the house if my help is needed

____I practice the family religion or philosophy.

____I am a sexual partner to my wife.

____I decide when the family is still divided after discussing something.

____I represent and advance my family in the community.

____I manage the family income and finances.

Check to see that you have a different number from 1 to 9 for each statement above. Each number should represent the order in which you actually carry out these roles in your family situation as it really is at the present time. Number 1 is the most important and number 9 is the least important.

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Form #1--b
2537-P

MARITAL ROLES INVENTORY

	p	np
H		
W		

Below is a list of functions or roles of the American wife and mother arranged in a random or haphazard order. Please read all the statements.

After you have read all the statements decide which one you want or prefer your wife to carry out as her most important function or role in your family situation as you would like it to be. Give it number 1. Then decide which one you want or prefer your wife to carry out as her next most important function or role in your family situation as you would like it to be. Give it number 2. Then number the other statements in the same way until you have a different number from 1 to 8 for each statement.

There is no correct order for these statements. One order may be as good or better than another depending upon the circumstances. Remember: Number these statements from 1 to 8 in the order of importance in which you want or prefer your wife to carry out these roles in your family situation as you would like it to be.

WIFE'S ROLES (H)

____She helps earn the living when her husband needs her help or when the family needs more money.

____She practices the family religion or philosophy.

____She is a companion to her husband.

____She is the homemaker.

____She is a sexual partner to her husband.

____She represents and advances her family socially and in the community.

____She manages the family income and finances.

____She decides when the family is still divided after discussing something.

Check to see that you have a different number from 1 to 8 for each statement above. Each number should represent the order in which you want or prefer your wife to carry out these roles in your family situation as you would like it to be. Number 1 is the most important and number 8 is the least important.

Development of the Short Forms of the Hurvitz Marital Roles Inventory

By the end of the demonstration portion of the project, the Hurvitz Marital Roles Inventory had been completed by forty-seven husbands and thirty-nine wives. However the concept of rank ordering appeared difficult to many of the respondents, and while they could usually pick out the one or two roles most important, and the one or two least important roles, they did not seem to be carefully discriminating with the ones left in the middle. In analysing the results, there were four items which were almost never given high rankings (less than 10% of the responses) while four others were consistently ranked high (more than 25% of the cases). In order to better facilitate administration of the form, and to allow for more careful discrimination among the four highly ranked roles, we shortened the inventory to only these four items. The instructions were also changed somewhat and the "I" form eliminated. Only a "he" form and a "she" form were retained. Copies of the revised forms are presented on the following two pages.

HURVITZ MARITAL ROLES INVENTORY

(Short Form)

Research Department
CURATIVE WORKSHOP OF MILWAUKEE
Form #1AD (2537-P) Revised
Copyright 1961 by Nathan Hurvitz, Ph.D.

	P	NP
H		
W		

Case # _____
Name _____
Date _____

INSTRUCTIONS:

Below is a list of possible roles for an American husband. They are all important but we would like you to arrange them in order of their importance at this time. Put a 1 in front of that role which is most important, a 2 in front of that role which is second most important, etc.

Husband's Roles

Ranked by: H_____ W_____

_____ He is a companion to his wife.

_____ He helps his wife with the homemaking if needed.

_____ He supports the family.

_____ He does his jobs around the house.

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HURVITZ MARITAL ROLES INVENTORY

(Short Form)

Research Department
CURATIVE WORKSHOP OF MILWAUKEE
Form #1BC (2537-P) Revised
Copyright 1961 by Nathan Hurvitz, Ph.D.

	P	NP
H		
W		

Case # _____
Name _____
Date _____

INSTRUCTIONS:

Below is a list of roles of an American wife. They are all important but we would like you to arrange them in order of their importance to you at this time. Put a 1 in front of that role which is most important, a 2 in front of that role which is second most important, etc.

Wife's Roles

Ranked by: H_____ W_____

_____ She practices the family religion.

_____ She is a companion to her husband.

_____ She helps support the family when this is necessary.

_____ She is the homemaker.

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Roles Inventory

Next a Roles Inventory, patterned after the Hurvitz Marital Roles Inventory, was constructed in such a way that the items were specifically related to the roles of a stroke patient and his (her) spouse. The patient form includes such items as, "I try to cause as little trouble as possible by doing as much for myself as I can." The non-patient form includes equivalent items such as, "He tries to cause as little trouble as possible by doing as much for himself as possible." The Marital Roles Inventory scoring procedures were applied to the Roles Inventory. The patient was instructed to rank his (her) own roles and those of the spouse; the spouse ranked his (her) roles and those of the patient.

Again, in order to save space we are presenting only two pages of the eight page inventory. We have included the pages which inventory the husband-patient roles as perceived by the husband-patient and the wife-non-patient roles as seen by the husband-patient. On the omitted six pages, only the pronouns are changed in order to be in accord with who is doing the perceiving.

Research Department
Curative Workshop of Milw.
Form #3-b
2537-P

	P	NP
H	x	
W		x

ROLES INVENTORY

Name _____ Date _____

Below is a list of functions or roles of the American husband who is a stroke patient arranged in a random or haphazard order. Please read all the statements.

After you have read all the statements decide which one you carry out as your most important function or role in your family situation as it really is at the present time. Give it number 1. Then decide which one you carry out as your next most important function or role in your family situation as it really is at the present time. Give it number 2. Then number the other statements in the same way until you have a different number from 1 to 8 for each statement.

There is no correct order for these statements. One order may be as good or better than another order depending upon circumstances. Remember: Number these statements from 1 to 8 in the order of importance in which you actually carry out these roles in your family situation as it really is at the present time.

Husband's Roles (H)

_____ I try to cause as little trouble as possible by doing as much for myself as I can.

_____ I have taken over those of my wife's duties that I can in order to help her out.

_____ I am planning and striving toward returning to work.

_____ I practice the exercises shown me in order to speed up my recovery.

_____ I try to get out and see people or encourage them to visit.

_____ I talk with my wife about our problems and how we are going to handle them.

_____ I entertain myself when my wife is busy and can't join me.

_____ I try to understand if my wife gets angry or upset.

Check to see that you have a different number from 1 to 8 for each statement above. Each number should represent the order in which you actually carry out these roles in your family situation as it really is at the present time. Number 1 is the most important and number 8 is the least important.

Research Depar.nent
Curative Workshop of Milw.
Form #3-a
2537-P

	P	NP
H	x	
W		x

ROLES INVENTORY

Name _____ Date _____

Below is a list of functions or roles of the American wife of a stroke patient arranged in a random or haphazard order. Please read all the statements.

After you have read all the statements decide which one you want or prefer your wife to carry out as her most important function or role in your family situation as you would like it to be. Give it number 1. Then decide which one you want or prefer your wife to carry out as her next most important function or role in your family situation as you would like to to be. Give it number 2. Then number the other statements in the same way until you have a different number from 1 to 8 for each statement.

There is no correct order for these statements. One order may be as good or better than another depending upon the circumstances. Remember: Number these statements from 1 to 8 in the order of importance in which you want or prefer your wife to carry out these roles in your family situation as you would like it to be.

Wife's Roles (H)

_____ She helps me whenever I really need it.

_____ She has taken over those duties which I can no longer do.

_____ She has a job or is hoping to get a job.

_____ She helps me do the exercises shown me in order to speed up my recovery.

_____ She encourages people to visit, and encourages me to go out.

_____ She talks about our problems and how we are going to handle them.

_____ She watches TV, plays cards, or otherwise spends time with me.

_____ She tries to understand if I get angry or upset.

Check to see that you have a different number from 1 to 8 for each statement above. Each number should represent the order in which you want or prefer your wife to carry out these roles in your family situation as you would like it to be. Number 1 is the most important and number 8 is the least important.

Short Form of the Roles Inventory

The same problems of administration and the same patterns of scores were obtained on the Stroke Roles Inventory as on the Hurvitz Marital Roles Inventory described earlier. Therefore these forms were also shortened to four items each and the "I" pronoun form dropped. Examples of the revised form follow this page. The example included asks the husband-patient to rank his roles and those of his wife-spouse. The only difference between the form for men patients and that for women is that the male form speaks of a return to work while the female form speaks of a resumption of homemaking.

(Short Form)
STROKE ROLES INVENTORY

	P	NP
H	X	
W		X

Research Department
CURATIVE WORKSHOP OF MILWAUKEE
Form #3BD (2537-P) Revised

Case # _____
Name _____
Date _____

INSTRUCTIONS:

Below is a list of possible roles for a husband who has had a stroke. They are all important but we would like you to arrange them in order of their importance to you at this time. Put a 1 in front of that role which is most important, a 2 in front of that role which is second most important, etc.

Husband's Roles

Ranked by: H_____ W_____

_____ He plans to return to work.

_____ He entertains himself while his wife is busy.

_____ He does as much for himself as possible.

_____ He takes over some of his wife's duties in order to help her.

STROKE ROLES INVENTORY
(Short Form)

Research Department
CURATIVE WORKSHOP OF MILWAUKEE
Form #3AC (2537-P) Revised

	P	NP
H	X	
W		X

Case # _____
Name _____
Date _____

INSTRUCTIONS:

Below is a list of possible roles for the wife of a person who has had a stroke. They are all important but we would like you to arrange them in order of their importance to you at this time. Put a 1 in front of that role which is most important, a 2 in front of that role which is second most important, etc.

Wife's Roles

Ranked by: H_____ W_____

_____ She entertains, and spends time with, her husband.

_____ She takes over those duties which he can no longer do.

_____ She helps her husband whenever he really needs it.

_____ She tries to understand if he gets angry or upset.

F. Inventory of Goals

The third and last of the attitude inventories was an Inventory of Goals to measure goal agreement between spouses. This was modeled after The Measurement of Goal Agreement Between Husbands and Wives by Pouson, Warren and Kenkel which was developed on farm families.

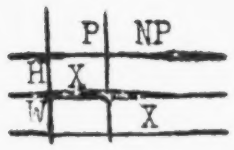
The adaptation to our purposes was made by devising a list of ten goals believed to be appropriate to stroke families, such as, "that he (she) will be able to use his paralyzed arm again". There are three separate forms: patient, non-patient husband and non-patient wife. The ranking prodecure is for the subject to first check "those goals which you think you will reach someday." The subject then reviews the goals and assigns rank order numbers to the five most important goals.

A tabulation of this data permitted a composite rank-ordering of goals as perceived by stroke patients, by the husbands of patients, and by the wives of patients respectively. In addition, it enabled the degree of correspondence between the goals of each couple to be computed.

To save, space, we have presented the Inventory of Goals given to the patient's husband and the form for the patient's wives. We have omitted the comparable inventory for the patient since the wording remains the same except for changing the pronoun from "he" or "she" to "I".

Since the Inventory of Goals was designed to measure patient and spouse expectations of therapy, it was deemed inappropriate to re-administer it at followup.

Research Department
Curative Workshop of Milw.
Form #2--b 1/22/68
2537-P



INVENTORY OF GOALS

In order to help disabled people it is important to know their goals.

Below is a list of 10 goals which you may hope your husband will reach someday.

First: Go through the list and in the left hand column check those goals which you think he may someday reach.

Then: In the right hand column, number the five most important goals, with number one being the most important and number five being the least important.

Check	Number 5 only	
____	____	that he will be able to work
____	____	that he will be able to use his paralyzed arm again
____	____	that he will be able to take the bus, walk or drive somewhere he wants to go so that he can get out of the house once in a while
____	____	that he learn to speak again
____	____	that he will be his old self again
____	____	that he learn some sort of activity or hobby to give him something to do
____	____	that he will learn to read and write again
____	____	that he will be able to walk again
____	____	that we will be able to visit and entertain relatives and friends again
____	____	that he will be able to take care of himself in everyday self care (bathing, eating, dressing, toileting)

Now go back and make sure you have listed the five most important goals with number one being the most important and number five being the least important.

Research Department
Curative Workshop of Milwaukee
Form #2--a 1/22/68
2537-P

	P	NP
H		X
W	X	

INVENTORY OF GOALS

In order to help disabled people it is important to know their goals.

Below is a list of 10 goals which you may hope your wife will reach someday.

First: Go through the list and in the left hand column check those goals which you think she may someday reach.

Then: In the right hand column, number the five most important goals, with number one being the most important and number five being the least important.

Check	Number 5 Only	
____	____	that she will be able to take care of the house
____	____	that she will be able to use her paralyzed arm again
____	____	that she will be able to take the bus, walk or drive somewhere she wants to go and get out of the house once in a while.
____	____	that she will learn to speak again
____	____	that she will be her old self again
____	____	that she will learn some sort of activity or hobby to give her something to do
____	____	that she will learn to read and write again
____	____	that she will be able to walk again
____	____	that she will be able to visit and entertain relatives and friends again
____	____	that she will be able to take care of herself in every-day self care (eating, dressing, bathing, toileting)

Now go back and make sure you have listed five most important goals with number one being the most important and number five being the least important.

CHAPTER 2

MISCELLANEOUS INNOVATIONS

Innovations in Casework Mechanics

Counselors were provided with portable tape recorders and encouraged to dictate home visits as soon as possible after the interview. The case recording process was divided: the counselors supplied only the initial rough report; the research assistant reorganized and edited these. For training purposes fifty-one of the case reports were mimeographed and distributed to agency staff members ahead of the staffing conference in order to make the staffing discussion more meaningful. The format of the staffing conference was altered to permit the casework report to be presented immediately after the physician's report.

After a year's experience, we found that the editing of counseling reports by a college graduate-research secretary was highly effective in saving counselor time, improving the wording of the reports, and getting reports out more nearly on time.

Research clerks and secretaries were utilized in a variety of ways to save the counselor's time and assist the client. The diverse talents of this college level clerical staff were fitted to the special demands of the situations. Some of the services provided by these sub-professional personnel to the counselor and/or client were:

1. Gathering purely factual data for Agency reports
2. Helping clients fill out forms (medicare, blue cross, etc.)
3. Telephoning agencies to check on progress of client's applications
4. Contacting business associations and service companies to see what special programs they might offer to disabled people
5. Notifying families of, and referring them to, special services available to them (library loans, talking books, tax credits, foodstamps, etc.)
6. Making daily telephone contact with isolated client in poor health
7. Patient-sitting for spouse of severely disabled client so he could go shopping
8. Transporting clients to doctor's, dentist's or other urgent appointments when no other alternative was available
9. Visiting homes to see if assistive devices could be installed
10. Teaching games to clients
11. If a question requiring factual information arose while the counselor was conducting a home interview, the counselor telephoned the office, a research clerk or secretary would find out the information about community resources available or whatever the problem was, and telephone the information to the counselor while the counselor was still at the patient's home.
12. In the same way when a question of fact about the availability of community resources or related problems arose during a staff conference, a research clerk or secretary was asked to find out the information by telephone, and report it immediately to the conference. In this way, the information became available upon which to make a decision without either interrupting the conference or postponing the decision

We believe all of these techniques have great possibilities for further development and significant improvement in the efficiency of case work. We were not able to demonstrate their efficiency because they were used only incidentally on a pilot basis. We found that the Project counselor, during the latter part of the domonstration when these techniques had been developed, only occasionally used the support provided. At one point she quipped, "you have provided me with so much back up support that I no longer have any excuse for being inefficient and this makes me nervous!"

We suspect that neither social workers nor rehabilitation counselors are taught how to function with this kind of back up support and that it is a major work role adjustment for them to meet the higher demands that it makes of them.

Recording Forms as Conceptual Tools

Innovations in forms may be useful in simplifying clerical work or in patterning thought. The Family Tree Form, No. 30, shown on the following page merely simplifies clerical work. It permits kinship relationships through three generations to be presented in chart rather than in narrative form.

The "Transportation Schema for Local Travel", Form No. 16, on the second page following, was developed in response to the continuing problem of transporting patients to and from the rehabilitation center. Many rehabilitation project reports cite this as a major stumbling block to rehabilitation activity.

It is our contention, based on observation of our own patient sample, that severely disabled patients fail to use the social mechanisms used by non-disabled people to solve their transportation problems. Non-disabled people form car pools to transport themselves more economically to and from work. Individuals who drive separately trade off - if one person's car is being repaired, he asks a co-worker to drive him to work and in turn reciprocates when his co-worker friend needs a ride.

In our patient sample, we found that few of our patients or their families met their transportation problems through cooperative effort with others. The "Transportation Schema for Local Travel" form was developed as a counseling tool to help the patient and/or his family to explore the various transportation alternatives. We were especially concerned with the social relationships involved, with how patients and their families could overcome their defeatist withdrawal attitudes, and with how they interact with other people to cooperatively solve their transportation problems.

Using this schema, the Supervisor of the Agency Activities Program was instrumental in arranging a car pool in which one patient transported several other patients to the Activities Program.

FAMILY TREE

(case #) _____ (name) _____

(father) _____ (mother) _____ (father) _____ (mother) _____

patient's siblings

_____

_____

_____

(patient) _____ (spouse) _____

spouse's siblings

_____

_____

_____

children

grandchildren

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Form #30 11/5/68

P NP
H
W

Transportation Schema for Local Travel

PUBLIC TRANSPORTATION: Type of Assistant Required

TYPE OF PUBLIC TRANSPORTATION	self	spouse	relative	friend	neighbor	co-worker	paid attendant	paid driver	fellow client
bus									
train									
subway									
taxi									
Handicab, proprietory									
Handicab, cooperatively owned									

PRIVATE TRANSPORTATION: Driver and Type of Assistant Required

METHOD OF PAYMENT	self	spouse	relative	friend	neighbor	co-worker	fellow client	paid attendant	car pool
free									
drive alternately									
pay own share of expenses									
pay more than own share of expenses									
hire driver									
hire attendant									
hire car plus driver plus attendant									
agency pays									
DVR transportation allowance									

Form No. 16 2537 P
Research Dept. 1/21/70
CURATIVE WORKSHOP OF MILWAUKEE

CHAPTER 3

RESEARCH UTILIZATION

An article steming from the review of the literature necessary to develop the Milwaukee Activities of Daily Living Inventory (MADLI) entitled "A Critical Review of 12 ADL Scales" by Terrill L. Bruett and Robert P. Overs was published in the Journal of the American Physical Therapy Association Vol. 49, No. 8, August 1969.

An article by the Project Director entitled "A Model for Avocational Counseling" was published in the Journal of Health, Physical Education and Recreation, Vol 41, No. 2, 1970. About 150 reprints of this have been distributed upon request.

About 700 requests for the Avocational Activities Inventory (AAI) have been received from all over the country and free distribution has been made of these. The Los Angeles Technical Service Corporation has incorporated our avocational activities classification structure in an overall plan they prepared for the Greater Los Angeles Youth Advisory Council. Their plan is a master check list of occupational, educational and recreational activities which should be made available to youth.

The Project Director has described the Avocational Activities Inventory, the Avocational Activities File, and the theory of avocational counseling at three professional meetings: the American Personnel and Guidance Association Convention, Las Vegas, April, 1969; the Annual State Conference of the Wisconsin Park and Recreatinn Association, Racine, Wisconsin, November 1969; and the Annual Institute of the National Therapeutic Recreation Society, Philadelphia, September 1970.

Written information about activity programs for the severely disabled was distributed to 14 churches and 2 housing developments. This was done during the exploratory survey of available sites in which to establish satellite centers for neighborhood activities programs for the disabled.

CHAPTER 4

DISCUSSION AND CONCLUSIONS

This project was based upon the idea that the family, rather than the individual patient, should be the focus of attention in the effort to rehabilitate stroke victims. This view is supported by considerable sociological and counseling theory. Stein (1969-family) presents an historical overview of the development of this concept. Increasingly the family has come to be seen as an integrated system of reciprocal roles. Under this approach, the family, as a unit, functions adequately or inadequately according to the degree of integration among the role perceptions and performances of the various members. By definition, roles are reciprocal in nature. A person's self-concept is based both upon his perception of the roles he can, and should perform vis-a-vis the others in his environment, and his estimation of the roles these others will wish to play towards him. His mental health and adjustment will depend upon how accurately he has gauged his own ability and the expectations of the others. Maladjustment occurs when the individual's own perceptions of his own or the other's roles do not coincide with the other's view of the respective roles.

Under this theoretical framework it does not make sense to talk of "individual" pathology. So-called "sick" or "maladjusted" members of the family system interact with "well" or "adjusted" members and it is this system of interaction that has produced the pathology. Thus it is the system itself which must be investigated. Friedman (1964 - family), Hurvitz (1967 - family) and Tharp (1966 - family) have all elaborated on this concept in detail.

Some marital counselors and family theorists have come to define marital success or adjustment in terms of the congruence between husband and wife perceptions of their respective roles. Dyer (1962 - family) points out that the problem facing newlyweds is exactly one of defining their role expectations and performances. Hurvitz, (1961 - family) has developed a whole counseling approach based on the agreement between husband and wife perceptions of roles. Tharp (1963, 1966 - family) and Kotlar (1965 - family) have found relationships between congruence of role perceptions and marital adjustment. Heer (1962 - family) and Stuckert (1963 - family) have indicated that there are differences in the degree of disparity according to the social class of the couples. While it is difficult to come up with a precise definition of exactly what marital or family adjustment consists, an operational definition comes easier. If a family is still together as a family, that is, not divorced or separated, we can assume that some accommodation with the environment has been established, however marginal or minimal. The patterns of interaction and task performance are sufficiently well integrated to keep the system surviving, if just barely.

A crisis is that kind of event or situation that would make the established pattern of role performance inadequate. A re-evaluation of the performances expected of each member of the family system is necessary. Roles must be reshuffled, at least temporarily. Kosa (1965 - family) distinguishes between a crisis situation and a chronic stress situation in that the latter requires a permanent changing of roles. Adjustment to the crisis is related to the degree to which the realignment of roles is satisfactory to each of the family members. This in turn is dependent on their ability to perceive what roles have been changed and how. Chronic illness or disablement would be an example of a chronic stress situation. Even non-chronic illness would require a temporary adjustment. Being disabled or sick is itself a role with its own set of

self- and other- expectations of performance. Thus the concept of "sick-role" has been developed. All the best efforts of rehabilitation personnel are for naught if the family encourages the patient in his sick-role performance. Thomas (1966 - general) in his "Problems of Disability from the Perspective of Role Theory" and Kassebaum (1965 - general) in "Dimensions of the Sick-Role in Chronic Illness" both provide theoretical support for the importance of the sick-role as a factor in rehabilitation. Starkey (1967 - general) provided empirical evidence to support the theory. Subjects matched for extent of cardiac impairment were found to differ in success of rehabilitation according to the extent to which they saw themselves as disabled. Bell (1966 - general) and Deutsch (1960 - family) showed the influence of family member and co-worker expectations on the adjustment of the patient. If others expected the patient to be dependent, then he usually was. When others expected the patient to contribute to the proper functioning of the family unit, then he was more likely to improve.

Aging itself, and retirement, have been described as crisis in role definitions. Ballweg (1967 - family) describes the adjustments of couples to the husband's retirement, and Phillips (1956 - general) describes the relationship of adjustment to one's self-image as aged.

A stroke would present a full crisis to the family system. Whether it occured to the husband or wife, an almost life-long pattern of performance with its corresponding self-concept would be brought to a halt. The victim would be at least temporarily, rendered incapable of performing any roles (crisis stage) and permanently hindered in the performance of many (chronic stress stage). Other family members would have to take up the slack. The patient and others would have to be aware of what changes have been made and by whom. Olsen (1966 - stroke), Straus (1967 - stroke), Barrow (1962 - stroke), Derman (1967 - aphasia) as well as Overs (1967 - stroke) have all suggested the need for family education in stroke care.

The medical professions as well as the counseling have also come to see the family as the unit of rehabilitation, although as Brodsky (1967 - family) points out, the differing professions themselves require different approaches towards the family. She outlined some of the differences between the role relationships in the physician-family and the psychotherapist-family dyads. Our approach was to focus on the family as a system, educate the members with respect to what a stroke was and its effects were, and through counseling facilitate **and** encourage necessary role changes. Such changes we would consider as evidence of good adjustment to the stroke.

At least logically, the possibility of role-changing or role reversal presented itself. Christopherson (1960, 1963 - family) developed an elaborate theoretical schema of the potential for role changes by the disabled man or the disabled woman. The disabled man could take over the housework while the wife goes to work; the disabled woman could concentrate on the affective, emotive aspects of her wifely role and serve as "enabler" or "setter of mood" for the husband or children. The implications for counseling **were** many and we are indebted to Christopherson for much of the counseling theory of our project.

In order to help the counselor identify possible instances of role conflict, and to estimate the relationship between congruence of role perceptions and ability to adapt to the stroke, we developed a set of inventories. These are described fully in Volume II, Chapter 1, "Instrumentation". They are patterne

after the published inventories of Hurvitz (1961 - family), Poulsen (1966-family) and Suinn (1966).

In retrospect we over-estimated two factors: one, the ability and desire of our population to assimilate and use cognitive information in decision-making; and two, the ability and receptivity of our population to change roles.

Probably the single most important influence on a person's actions or decision is the person's attitudes, beliefs, and values. To describe the development of these, or to explain the distinctions among them, is fraught with philosophical and sociological hazards. It does seem to be generally agreed that as structuring and ordering devices, attitudes, beliefs and values precede logical thinking and do not derive from logic or rationality. Therefore, the influence of basic attitudes, beliefs, and values, on actions or decision is primarily of an emotional, not an intellectual nature. This is more evident with the lower the educational development of the people concerned. Therefore, to expect cognitive or factual data to greatly influence the decision making process of a group at the educational level of our families was not realistic. One value or attitude a person could have that would definitely affect his willingness to change roles would be a feeling that change itself is bad, that things should stay the same. This rigidity is a compulsive seeking of permanence, of stability. A HEW publication, Working with Older People (1970), reports that "rigidity in an individual is associated with the extent of schooling and the number of years that have passed since school was attended." On both counts our families could be expected to be rigid. They were.

On all the variables which we selected as possible areas for role change, the families were noticeably reluctant to make any fundamental changes. There did not seem to be any greater degree of role changing in those 21 families exposed to "intensive" casework than in the other families. Whether such role changes are indeed indicative of adjustment to a stroke remains an unanswered question. Families do not operate in a sociological vacuum and changes in family role assignment must be acceptable to the community at large. Family members must perceive that society will allow them to act in a certain way, and in fact expects them to act in that way, before they can decide on their appropriate roles. To expect persons of advanced age, low education, and impaired physical and mental functioning to reallocate their family roles in a manner directly contradictory to the norms of the society at large seems presumptuous in retrospect. Whether younger families, brought up under different conditions would be more amenable to role switching is still to be seen.

However, while the Project did not demonstrate that intensive casework with stroke families would result in adaptive role changes, it did provide a wealth of statistical data on the contemporary urban family in general, and the older families with a disabled member in particular.

Although our sample was small, we feel our findings serve to support and extend the theoretical implications of such earlier studies as those by Blood (1960 - family) and Centers (1971 - family) on the urban family; by Ballweg (1967 - family) on retirement families; by Artes (1967 - stroke) and Haese (1970 - stroke) on stroke families; by Brown (1968 - general) and New (1968 - stroke) on the perception of disability and by Christopherson (1960, 1963 - family) on the possibility of role changes. There were differences in the size, scope, design, purpose and findings between our project and these others, as well as among the others themselves, but these differences serve only to make the similarities the more significant.

Blood (1960 - family)and Centers (1971 - family) interviewed more than 700 families each, in Detroit and Los Angeles respectively. The purpose of both studies was to ascertain the relative power of the husband and wife in the contemporary American family. They did this by asking a random sample of husbands or wives (not couples) to describe who had the final say in making certain decisions, or performing certain tasks. Their respondents were of all ages, were not disabled, and did not have their spouses present. Our respondents were old, disabled and half the time had a spouse present during the interview. However, all three studies revealed a pattern of marked sex specialization in terms of division of household labor. Family decision-making tended to be more equalitarian. This would seem to indicate that our families were not unique in their perception of the usual division of household tasks.

All three studies also found that companionship was the most important aspect or role of marriage for the respondents. Romanticists take heart! This has implications for counseling in an era when work, in or out of the home, takes up less and less of the day.

Ballweg (1967 - family) interviewed 52 urban housewives whose husbands ranged in age from 65 to 82. Some of the husbands were still working; others had retired. The two groups were compared as to the division of labor between husband and wife on 12 household tasks. Differences between the two groups were slight, the retired husbands performing only slightly more of the housework than their still-working counterparts. Those jobs they did take over were usually the more "masculine" in nature. Blood (1960 - family) also found that non-working husbands usually "puttered" around the house rather than sharing the housework. Our findings agree with these and further suggest that the reason is not so much laziness on the part of the husbands as rigidity on the part of the wives. Our findings show that disabled husbands said they were willing to take over some of the household tasks but that the wife did not want this intrusion into her sphere of responsibility. Perhaps new roles outside the home could be found for the retired or non-working husband.

Artes (1967 - stroke) interviewed the wives of 65 former stroke patients in their homes. These families were pre-selected from an original sample of 345 former patients. The families were all from the Iowa City area of Iowa and median time from onset of stroke to interview with wife was 19 - 24 months. Husbands were not present for the interview which consisted of 271 items, mostly yes/no or multiple choice items, but there were a few open-ended questions.

Haese (1970 - stroke) interviewed 20 former patients from metropolitan Milwaukee in their homes on a 60 item yes/no questionairre about 3 years after discharge from the hospital.

We interviewed 88 former patients in their homes in metropolitan Milwaukee and half of the time their spouses were present. Average time since admission to the Agency was 22 months and the interview schedule consisted of 92 items, worded to elicit short answers.

All three studies concluded that stroke families are not given sufficient information regarding strokes and their effects. In all three studies 40 - 50% of the respondents indicated that their doctors had not adequately described a stroke to them. In the Artes study (1967 - stroke) and our own, finances were not mentioned as an overwhelming problem although almost all families had cut into their savings and had been forced to change their spending habits. Neither group of families had undergone much change in their living situation, most

still living in their own or a child's home. Few of the men patients returned to work, started new avocational activities, or helped much with the housework. Few of the spouses had started working to supplement the family income. Physical changes were most frequently mentioned as being the chief problem since the stroke, and the main reason for the drop in activity level. However, in both groups the majority of patients were rated by their spouses as independent in most activities of daily living.

In both Haese and our own studies, the majority of patients felt therapy had helped them and all three studies found that the support of family and friends was a great help to the recovery from the stroke.

A major theoretical assumption of our project was that families must make decisions about patient care and safety, and these decisions can lead to maladjustment if the different family members have different perceptions of the extent of the patient's ability. We asked therapists, spouses and the patients themselves to make separate evaluations of the patient's ability to perform nine activities of daily living. These separate ratings were then compared to see what differences there were. The activities scale used (MADLI) is described in Volume II, Chapter 1, "Instrumentation." Brown (1968 - general) and New (1968 - stroke) did similar studies and came up with similar findings. Patients, spouses and therapists are not always in agreement as to what the patient can do. When the patient describes himself as dependent, the others usually agree; but when the patient describes himself as independent there is less agreement. Spouses tend to be more conservative than the therapists. It could be that both spouses and therapists are perpetuating patient dependency.

Christopherson's studies (1960, 1963 - family) suggested that counseling should be aimed at fostering changes in the family role structures that are more in line with the changed physical and mental capacities of the family members. We agree. However, our population did not respond with many such changes and neither did Christopherson's. Only 22% of the men in his sample assumed more than 25% of the housework and his sample was considerably younger than ours. We, like Christopherson, found differences between the patient's self-description and the spouse's patient-description. Again, in both studies there was a general tencency for the spouses to be harder on the patient than he was on himself.

There has been a lot said about the death of the extended family and its implications for urban living. It has been assumed that interaction among relatives has decreased as the trend towards nuclear household units developed. However, our project showed, and some other recent studeis have also found, that it is not so much the family that is dying as the neighborhood. Eighty per cent of the interaction our patients had was with family or relatives. Less than 10% of the interaction was with neighbors. This corresponds to Rosenberg's (1970 - aging) findings in Philadelphia where nearly 90% of his sample of older workers saw at least one relative a week. Other estimates of the elderly's contact with their children show that few of the older people are out of touch with their children (HEW, 1970 - aging, Rodman, 1965 - family and Youmans, 1967 - aging). From a third to a fourth are estimated to live with an adult child. Our sample found 28%. Another half of the patients are supposed to live within walking or a short ride's distance from a child. Our findings agree.

Nor do the children merely visit. Help is usually available if needed, more often supplied by a daughter than a son, and usually by one child of the family more than the others. The difficulty arises from the fact that as our

cities decay, the children no longer live in geographical proximity to the patients. Visiting, even when it involves a walk or a short ride, can be a major expedition in some of our cities. Thus the demands made on the helper can be disproportionate to the actual help itself. Neighbors would be in a better position to give some types of help, but it is the neighborhood interaction that is missing. When children, relatives, and neighbors were all the same set of people there was no problem. As the proportion of children and relatives in the neighborhood or nearby area declines, the demands on each one of those remaining increase. What might have been an easy task when spread over three or four nearby relatives, can be a severe drain on the emotional resources of the one child remaining in the area. Christopherson describes the danger of "locked" relationships (Donahue, 1969 - family). He suggests more thought be given to how patients can help their helpers. Our findings indicate that babysitting and child care could be utilized to a much greater degree. Further evidence of the breakdown of a community consciousness was presented by the relative lack of knowledge our patients had of existing community services and programs. Most were known to only about half the families and fewer still were ever used. There was some evidence that counselors were effective in increasing the families' knowledge of the service available.

It seems that it was unrealistic to expect a counselor to effect major changes in the life style of families after a major catastrophe like a stroke. The basic instinct of people under stress is to hold to previously proven patterns of action whether these are effective in the new situation or not. The whole life style of our population, and seemingly of other studies such as Artes (1967 - stroke) and Christopherson (1963 - family), is that of a traditional, conservative, sex-typed and inflexible division of roles, and a fairly limited array of roles at that. If just one or two items in the repertoire are eliminated, the whole show collapses. In Goffman's (1959 - general) terms, most of these people have never been encouraged to develop a wide range of "selfs" to present. Since longevity, enforced retirement, and shorter working hours are a fact of present day life, the problems faced by stroke families today are only a prototype of the ones all families will eventually have to confront.

One cannct overestimate the trauma of a stroke. It must be a frightening and shattering experience for all those affected, spouses and children as well as patients. However, it is our conclusion that a stroke does not change the basic approach to life, and the problems of life, that the individual and the family have been using the previous fifty or more years of life, and twenty or so years of marriage. The fact is that most people and families do not have a well-defined or well-developed philosophy of life or approach to problems. More fundamentally, they do not have well-developed self, or family, concepts. The society, its schools, its institutions, its values, have never encouraged them to develop one.

The HEW publication (1970 - aging) quoted above states that at the present time "if retirement income is adequate, a period of two years is about the usual length of time for personal adjustment to retirement to be achieved." This is a sad commentary on a society that prides itself on its ability to extend the life span and increase the percentage of leisure time. If two years are required for couples with "adequate income" and in good health, one hesitates to make an estimate of the time required for these families with a disabled member and strained financial resources. Our findings seem to indicate that by two years after the stroke, most families have reached some sort of an

equilibrium with their surroundings. After the immediate crisis period ends, and it becomes clear that no miracle to restore the lost function is about to occur, the family members pick up the pieces that remain and continue about as they did before, but at a reduced level. If their adjustment was marginal before the stroke, it is likely that the stroke will be the proverbial last straw. It is worth speculating that perhaps therapy merely prolongs the wishful thinking stage and does not encourage patients to face the fact that new roles, new patterns of interaction with the surroundings, are necessary.

It seems that gains made in therapy are not carried over to or maintained in the home because the gains made are not seen as relevant to the real-life needs of the families. Perhaps early and intensive counseling, before therapy even begins, might help the families define what they expect from therapy in more realistic terms than "return to work", or "make my arm better". Patients seem to look upon therapy as just another form of prescription medicine. It doesn't taste or look good, but swallow it anyway and maybe something will happen. They are not encouraged to play an active, planning role in the rehabilitation process. However, they have probably not been encouraged to play an active, planning role in many other areas of their lives either.

It seems unlikely, though, that counseling per se is the answer. Changing values, or long-established life patterns, is an extensive and expensive process. There is only slight evidence that psychotherapy of whatever type produces results more often, or more beneficial, than those produced simply by the passage of time.

One encouraging result of the project was the success of the Activities Program and the enthusiastic community response to preliminary efforts to extend it. It seems that small groups, perhaps located near or in the patient's own neighborhood, might be the most productive means of encouraging patient activity, especially for men patients who expressed a greater need to get out of the house. If nothing else, it would provide a setting where these unwilling pioneers of the leisure time frontier might work out new patterns and values that could serve as models for those of us who must surely follow.

CHAPTER 5

SUMMARY AND IMPLICATIONS

This chapter is a recapitulation in brief form of the summary and implications sections appearing at the end of the relevant chapters. In the right hand column entitled "Implications", we have suggested what the data immediately adjacent in the left hand column imply. Although this method has its hazards in that a cause-effect relationship may be improperly assumed, we believe that it is an effective way to point out what implications for current practices and further research the findings from the research suggest. Implications are judgements are made by the authors for which they are soley responsible. If the reader does not agree with the implications offered by the authors, we hope that it will at least stimulate him to draw from the data his own implications.

Included in this chapter are only those items we felt had the most important implications. Items including methodology and demographic materials were for th most part omitted and may be found in the various chapter summaries. Information presented in the SIGNIFICANT FINDINGS FOR REHABILITATION AND SOCIAL SERVICE WORKERS has also been omitted from this chapter.

Summary	Implications
Over two-thirds lived with spouse only, grown children or other relatives.	Most patients were tied into a family living style of life.
8 patients (8%) were in a nursing home at followup.	Fewer patients than was anticipated had to move into a nursing home.
The burden fell most heavily on one person - for men patients, 31% of the time the help was given by one son and 31% of the time by one daughter.	Psychological problems frequently arise when one person shares the entire burden of another's care.
For women patients, 43% of the help was given by one daughter and 14% by one sister.	Patient care is predominantly a part of the feminine rather than the masculine role.
For both sexes, over 80% of the people seen once a week or more were family members. Sixty-five per cent of those seen were a spouse or child. Daughters were seen exactly twice as often as sons.	The family social network continues to support the individual. The community network of social bonds has greatly diminished.
Only 9% of the people seen once a week or more were neighbors. Only 10% were friends. One per cent were co-workers.	Combining friends, co-workers and neighbors, we find 20% are non-family contacts. Of these, the neighbors, because of geographic propinquity, are the most useful for giving practical assistance at the right time.

Summary and Implications - Continued

Summary	Implications
Patterns of help were reciprocal. Whom the patients helped rather closely followed the pattern of who helped them. This says nothing about either the quality or amount of help given, only the distribution of help coming from and going to different categories of significant others. Thus, one daughter and one son headed the list of those receiving help.	Most patients need to develop more extensive patterns of mutual aid to meet their needs.
The most frequent kind of help given by patients was in child care, doing chores, providing living accommodations, financial assistance, and advice.	There may be opportunities for patients to contribute in the area of child care to a much greater extent than has been the practice.
Help given by someone outside the family amounts to only 11% for men patients, 16% for women patients. Neighbors account for 7% and 8% respectively.	There appears to be no breakdown in the mutual aid patterns of these urban families. The problem is in the breadkown of neighborhood aid. Since neighbors by definition live close-by, but family members are not necessarily so located, neighbors are in a better position to help

Degree of Isolation (N= 61 families)

Not isolated	10%	The fate of the patient and the family are closely dependent upon the increasing alienation of urban society. Although recent studies report a higher degree of social interaction in cities than previously believed, this has rarely been on a neighborhood basis. Stroke families need the physical and social interaction help which physically adjacent neighbors can give most effectively.
Marginally isolated (contact with more than one family in neighborhood)	5%	
Isolated from neighbors but contacts with formal organizations outside neighborhood	26%	
Isolated from neighbors - contacts with family and work group only	59%	

Attitudes toward their Neighborhoods (N = 51 families)

Complained of neighborhood changing	18%	The attitudes of stroke patients and their families towards neighbors are extremely dysfunctional. As indicated above, they desperately need the help which neighbors can give most effectively.
Neighbors unfriendly and don't care	24%	
Patients did not want to get involved	41%	
Patients were proud of not wanting to get involved	18%	

Summary and Implications - Continued

Summary	Implications
Only about 10% of the patients maintained any close relationship with other stroke patients once they left the Agency. Twenty-three per cent reported having contacts, but only infrequently in their home or the other patient's home.	There is a need for programs to ease the patient's transition from dependent patient to a peer in social relationships.
Before the stroke about two-thirds derived their income from wages and salaries and one-third were on social security. Now 72% received social security and only 30% relied on wages and salaries. The number receiving public assistance jumped from 3 (4%) to 7 (9%).	Any medical research money spent by the government which reduced the incidence of stroke or delayed the occurrence of stroke until an older age would be repaid through more income tax receipts and fewer social security disability and welfare payments.
The percentage of working wives of men patients decreased from before to after the stroke.	As a group, women do not reverse their sex role and become the wage earner to augment the family income.
When the wife was the patient more changes occurred in who performed household tasks. One-third or more of the families with women patients had to make some adjustment in each of the 21 activities.	When the wife is the patient, the family is more apt to need housekeeping care: either volunteer help or paid professional service.
When the husband was the patient, there were only 8 activities in which more than one-third of the families were affected.	When the husband is the patient, the family is more apt to need money.
On responses to questions about goals and marital roles, both patient and spouse reflected a conservative, traditional view of family and familial roles: husband as provider; wife as homemaker.	The values of society are more important than either medical condition or personality characteristics in the adjustment outcome of stroke families. The values by which this older group of individuals, with limited formal education, guide their lives are traditional and conservative and may no longer be characteristic of younger age groups with more formal education.

Summary and Implications - Continued

Summary	Implications
Companionship was selected as the main function of marriage.	Every effort should be made to avoid separating couples for purely "practical" reasons such as finances, easier patient care, etc.
Neither placed a high value on visiting, entertaining friends, or getting out of the house.	The logic of reciprocity in mutual help and social interaction is not supported by favorable attitudes towards it.
There were sharply separated spheres of responsibility for household chores, with disagreement between responses of husbands and wives over tasks.	Strokes upset the division of labor established over years of marriage and there is resistance to redefining the respective roles of the spouses.
Neither wanted to do the tasks together. The wife was not anxious to take over his duties nor to have him do hers.	The logic of reshuffling roles and duties is not supported by attitudes favorable to this.
Women patients put the husband's helping with housework as least in importance whereas their husbands placed it second.	Wives resist intrusion into their homemaker roles.
Husbands and wives, patients and non-patients all were agreed that the wife's place is in the home. All felt that the least important role she could perform is that of supporting the family.	The new values of the Women's Liberation Movement have not touched these families.
The women stroke patients ranked their homemaking role higher than their companionship role in contrast to the relative rankings given these items by all the men and the spouses of men patients.	There is a rigid, compulsive attachment to the homemaker role among these women patients.
None of the women patients felt it was most important for them to help the husband with his chores although almost one-fifth of the husbands thought it was.	There is a great reluctance to cross over sex roles.
Patients split on describing what is most important in adjusting to a stroke: passive (accept conditions) 35% active (ignore conditions) 28%	Which coping mechanism is used probably is determined by pre-stroke personality and adjustment patterns.

Summary and Implications - Continued

Summary	Implications
Men patients were described as: not very interested in life anymore, unwilling to fight fate, ready to give up except for the people helping them, feeling self-conscious about their disability, feeling that the disabled are different, feeling that people notice their disability, feeling that other people are uncomfortable in the presence of their disability.	Men and women stroke patients have different attitudes towards their disability and in general women seem to adjust better.
Women patients were described as: getting restless unless busy, having days pass slowly, feeling that being disabled can have advantages, hoping that they will be as good as new before long.	
As a group, spouses tended to rate patients lower than the patients rated themselves on ADL items (8% to 26%).	This may be highly significant in family decision-making concerning leaving the patient alone.
TV watching, card playing and reading were the most frequently selected and in that order. The percentages of people doing each remained fairly constant both between sexes and before and after the stroke.	Avocational counseling may well start by helping patients enlarge and enrich their activities within these areas.
It was unusual for a patient to continue an activity at a reduced rate. They usually either stopped completely (40% of pre-stroke activities) or continued at the same or even an increased level. Only about 13% of pre-stroke activities were continued at a reduced rate.	
Only 12% of the activities being performed had been started since the stroke. Women were more apt to do this (18%) than men (7%).	New techniques in avocational counseling are needed to motivate the patient to try new things.

AUTHOR - SUBJECT INDEX FOR VOLUME II

(note: Chapter 5 "Summary and Implications" is not indexed)

Author-- Subject	Page (s)
Activities of Daily Living (ADL)	6, 7 - 14)
Artes	55, 56, 58
Attitudes, patient	6, 8, 15, 21, 29 - 32, 33
spouse	15, 21, 27, 33
Avocational Activities	6, 7, 52
descriptions	6, 52
file	6, 52
Inventory	6, 52
Ballweg	54, 55, 56
Barrow	54
Bell	54
Blood	55, 56
Brodsky	54
Brown	55, 57
Bruett	7, 52
Casework	48
Centers	55, 56
Christopherson	54, 55, 57, 58
Counselors	48, 49
Counselor Aides	48, 49
Derman	54
Description by Spouse Scale	21, 22, 28
Deutsch	54
Donahue	58
Dyer	53
Family Tree	49, 50
Feldman	15, 16, 21, 28, 29, 31
Friedman	53
Goffman	58
Goals	6, 15, 45, 47
Haese	55, 56, 57
Heer	53
Hurvitz	21, 33, 34, 36 - 38, 53, 55
Instrumentation	6 - 47
Innovations in case work mechanics	48 - 49
Inventory of Goals	45, 47

AUTHOR - SUBJECT INDEX FOR VOLUME II - CONTINUED

Author - Subject	Page (s)
Kessebaum	54
Kenkel	45
Kosa	53
Kotlar	53
Marital Roles Inventory	33, 39, 42
Milwaukee Activities of Daily Living Inventory (MADLI)	7 - 14
New	55, 57
Olsen	54
Overs	7, 52, 54
Personnel	48
Phillips	54
Poulsen	45, 55
Research Utilization	52
Rodman	57
Roles	6, 8, 9, 15, 21, 33 - 44
Roles Inventory	39, 42
Rosenberg	57
Staffing conference	48
Starkey	54
Stein	53
Straus	54
Stroke Roles Inventory	43 - 44
Stuckert	53
Suinn	15, 16, 21, 28, 29, 31, 55
Suinn-Feldman Rehab. Self-Description Scale	15 - 21, 28
Suinn-Feldman Self-Description	29 - 30
Suinn-Feldman Spouse Description	31 - 32
Telephone Contact with Patients	48
Tharp	53
Thomas	54
Transportation schema for local travel	49, 51
Warren	45
Youmans	57

APPENDIX - TABLE OF CONTENTS

Section Title	Page
Agreement Between MADLI Ratings	iii
Comparison of Building Features	viii
Methodological Note on the Reliability of the Instruments	x
Excerpts from Content Analysis of Counseling Records	xi
Patient	xi
Spouse	xv
Children	xviii
Patient - Family	xix
Counselor	xxj
Contact with Agencies	xxvi

APPENDIX - LIST OF TABLES AND FORMS

Letter	Title	Page
A	Agreement by Rating - Pair on Dial Phone at Admission	iii
B	Agreement by Rating - Pair on Eating at Admission	iii
C	Agreement by Rating - Pair on Walking at Admission	iv
D	Agreement by Rating - Pair on Stairs at Admission	iv
E	Agreement by Rating - Pair on Transferring at Admission ...	v
F	Agreement by Rating - Pair on Dressing at Admission	vi
G	Agreement by Rating - Pair on Push-button Phone at Admission	vi
H	Agreement by Rating - Pair on Leg Braces at Admission	vii
I	Agreement by Rating - Pair on Wheelchair at Admission	vii
	Comparison of Building Features	viii

APPENDIX

Table A: Agreement by Rating-Pair on Dial Phone at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	24	18	75%	11	11	100%	35	29	83%
Pt. - Th.	29	23	79%	30	26	87%	59	49	83%
Pt. - Co.	16	14	88%	21	15	71%	37	29	78%
Th. - Co.	17	13	76%	21	15	71%	38	28	74%
Sp. - Th.	22	11	50%	12	8	67%	34	19	56%
Sp. - Co.	10	6	60%	5	3	60%	15	9	60%
Total	118	85	72%	100	78	78%	218	163	75%

C = Comparisons made; A = Agreement

This was the easiest item for most raters to agree on. Only the spouse-counselor and spouse-therapist pairs had less than 74% agreement. In the disagreements between these raters, the spouse usually gave the lower rating (17 of 21). In those few cases where the patient and therapist did not agree, it was the patient who rated himself lower (8 of 10). When the patient and spouse disagreed (only on male patients), the wife again gave the lower estimate (5 of 6).

Table B: Agreement by Rating-Pair on Eating at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	25	16	64%	12	9	75%	37	25	68%
Pt. - Th.	34	25	74%	30	22	73%	64	47	73%
Pt. - Co.	17	10	59%	22	18	82%	39	28	72%
Th. - Co.	18	12	67%	23	22	96%	41	34	83%
Sp. - Th.	25	16	64%	13	9	69%	38	25	66%
Sp. - Co.	10	6	60%	7	5	71%	17	11	65%
Total	29	85	66%	107	85	79%	236	170	72%

C = Comparisons made; A = Agreement

This was also an easy item for all pairs to agree on. There was not much difference between the percentage of agreement of the various pairs. The figures ranged from 65% to 73%, except for the therapist-counselor pair which did better (83%). When there were disagreements, the therapist most often gave a higher rating than did the patient or the spouse (26 of 30). The counselor also tended to rate the patient's performance higher compared to the patient's own, or the spouse's evaluation (14 of 17).

Table C: Agreement by Rating-Pair on Walking at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	26	21	81%	12	10	83%	38	31	82%
Pt. - Th.	31	22	71%	32	25	78%	63	47	75%
Pt. - Co.	18	12	67%	21	14	67%	39	26	67%
Th. - Co.	19	9	47%	24	15	62%	43	24	56%
Sp. - Th.	24	16	67%	13	11	85%	37	27	73%
Sp. - Co.	10	7	70%	7	6	86%	17	13	77%
Total	128	87	68%	109	81	74%	237	168	71%

C = Comparisons made; A = Agreement

Most of the pairs agreed between 67% and 77% of the time. The patient-spouse topped the list with 82% and the therapist-counselor were at the bottom with 56%. The counselor would not ordinarily have the opportunity to see the client walk. It is interesting to note that when there were disagreements, the patient was definitely more likely to give himself a higher rating than either the spouse (5 of 7) or the therapist (13 of 16).

Table D: Agreement by Rating-Pair on Stairs at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	24	17	71%	11	8	73%	35	25	71%
Pt. - Th.	29	22	76%	23	17	74%	52	39	75%
Pt. - Co.	17	10	59%	20	13	65%	37	23	62%
Th. - Co.	17	11	65%	18	14	78%	35	25	71%
Sp. - Th.	20	9	45%	9	6	67%	29	15	52%
Sp. - Co.	10	4	40%	5	4	80%	15	8	53%
Total	117	73	62%	86	62	72%	203	135	67%

C = Comparisons made; A = Agreement

This was one of the harder items to rank especially for the spouse-therapist and spouse-counselor pairs (only 52% and 53% agreement respectively). There was a slight tendency for the therapist to rate the patient higher than his spouse did (9 of 14). The clearest trend though is for the patient to give himself more credit than either his spouse or the therapist feel is justified (19 of 23) when they disagree.

Table E: Agreement by Rating-Pair on Transferring at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	23	13	57%	11	6	54%	34	19	56%
Pt. - Th.	31	23	74%	30	23	77%	61	46	75%
Pt. - Co.	18	8	44%	22	14	64%	40	22	55%
Th. - Co.	18	9	50%	24	12	50%	42	21	50%
Sp. - Th.	22	14	64%	12	9	75%	34	23	68%
Sp. - Co.	10	3	30%	7	5	71%	17	8	47%
Total	122	70	57%	106	69	65%	228	139	61%

C = Comparisons made; A = Agreement

The only pairs to agree much more than half the time on this item were the patient-therapist and the spouse-therapist (75% and 68%). In both cases, when they did not agree it was the therapist who gave the more conservative rating (20 of 26). Perhaps the therapists are more conscious of the technically correct (and safe) way to transfer while the patient and spouse are concerned only with the end result. The patient and spouse disagree quite often on this item and, in these cases, the patient thinks more highly of his ability than the spouse does (10 of 15).

Table F: Agreement by Rating-Pair on Dressing at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	25	16	64%	12	7	58%	37	23	62%
Pt. - Th.	32	21	66%	31	22	71%	63	43	68%
Pt. - Co.	18	7	39%	22	13	59%	40	20	50%
Th. - Co.	18	11	61%	24	19	79%	42	30	71%
Sp. - Th.	23	10	43%	13	6	46%	36	16	44%
Sp. - Co.	10	3	30%	7	4	57%	17	7	41%
Total	126	68	54%	109	71	65%	235	139	59%

C = Comparisons made; A = Agreement

This was the hardest item to rate, especially for men clients. Perhaps this is because all the other raters were women. There was no visible trend in the cases of disagreement either, with the exception of when the patient and counselor rated women clients. Here the counselor gave the higher rating the great majority of times (8 of 9).

Table G: Agreement by Rating-Pair on Push-Button Phone at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	4	4	100%	3	2	67%	7	6	86%
Pt. - Th.	4	3	75%	1	0	0%	5	3	60%
Pt. - Co.	-	-	---	-	-	---	-	-	---
Th. - Co.	-	-	---	1	1	100%	1	1	100%
Sp. - Th.	3	1	33%	2	2	100%	5	3	60%
Sp. - Co.	-	-	---	1	1	100%	1	1	100%
Total	11	8	73%	8	6	75%	19	14	74%

C = Comparisons made; A = Agreement

There are no evident differences, but very few ratings were made. This was only tried when the patient was not able to use a regular dial phone.

Table II: Agreement by Rating-Pair on Leg Braces at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	8	6	75%	2	1	50%	10	7	70%
Pt. - Th.	5	2	40%	9	5	56%	14	7	50%
Pt. - Co.	1	1	100%	6	5	83%	7	6	86%
Th. - Co.	1	1	100%	5	3	60%	6	4	67%
Sp. - Th.	4	2	50%	4	3	75%	8	5	62%
Sp. - Co.	2	2	100%	2	1	50%	4	3	75%
Total	21	14	67%	28	18	64%	49	32	65%

C = Comparisons made; A = Agreement

There are no evident differences between the rating pairs or between men and women cases. There are too few ratings to make valid comparisons with other items.

Table I: Agreement by Rating-Pair on Wheelchair at Admission

Pair	Men			Women			Total		
	C	A	%	C	A	%	C	A	%
Pt. - Sp.	8	5	62%	4	2	50%	12	7	58%
Pt. - Th.	9	5	56%	7	3	43%	16	8	50%
Pt. - Co.	4	2	50%	3	1	33%	7	3	43%
Th. - Co.	5	4	80%	2	1	50%	7	5	71%
Sp. - Th.	6	3	50%	5	2	40%	11	5	45%
Sp. - Co.	3	1	33%	3	1	33%	6	2	33%
Total	35	20	57%	24	10	42%	59	30	51%

C = Comparisons made; A = Agreement

There are too few ratings to evaluate, but no differences are evident.

Curative Workshop of Milwaukee
July 8, 1970

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Form #47 Page a

COMPARISON OF BUILDING FEATURES

Organization	Type of Building	Nearby Streets	Nearby Bus Routes	Room Type	Furniture Features	Times Available	Comments
W_____ Library	Civic Center	North-South 76th; E and W. North Avenue	North Ave. Bus	Large, visual room child library 50 people	Chaired, Carpeted floor	1/2 day	Room is used by children's librarian during the year for reading prq gram.
R_____ Church	Parish Home	27th St.		Fellowship One room	Chairs, tables		
C_____ D___ L_____ Church	Parish Fellowship room	Capital Drive	Capital Drive	Large Fellowship room, 50x 125, 4 small room, walls are dividers, 15'x15'	Tables, Chairs, Kitchenette		
W____ Housing Authority	Recreation Unit	E.W. Silver Spring	Silver Spring	20x25		p.m. only except Tuesday	Whole building is level

Curative Workshop of Milwaukee
Form #47 Page b

Loading Facilities	Parking Facilities	Storage Facilities	Architectural Features	Rest-Rooms: Distance	Access	Bars	Comments	Equipment
Driveway to entrance on 76th	Parking Lot	Not Available	One floor level to meeting room. Elevator to 2nd floor for handicapped who want to use adult library.				Facilities are children's size on 1st floor. A Morning or afternoon program at this location may be feasible-The use of crafts may be questionable or limited-library is attached to the Civic Center.	Projector
	none, street only		Steps from sidewalk (4) to church	Men's + Ladies Office			Community-orientated church serving Blacks-only valid reason for this church to be considered, in spite of architectural barriers, is the clients that could be served.	
	back of church		9 steps downstairs floor level to room, limited for seriously handicapped, wheelchair, etc.	Mens-40' Ladies-40'	level level 2 wide doors open on opposite sides to get into bath rooms	yes yes	Peddle operated flush, both bathrooms. 1. building is on ground level-2nd floors 9 steep steps up 10 steep steps down, railings both sides 2. activity room 50'x125' and kitchenette.	tables chairs
	yes		All level except 1	Mens 75' ladies-75'	level level	no no	30" doorways, 23" stalls same Mental Health, Out-station, group workers.	tables chairs

Methodological Note on the Reliability of the Instruments

Milwaukee Activity of Daily Living Inventory (MADLI)

To establish the reliability of the MADLI, physical and occupational therapists were asked to rate all the patients they treated over a certain two-week period on any item they felt competent to do so. Since patients have different therapists for different parts of therapy, and at different sessions, this provided several independent ratings for each patient on each item. Eleven therapists rated 18 patients on eight items for a total of 191 comparisons. The number of comparisons ranged from 36 on transferring to three on wheelchair, with an average of 24 per item. There was inter-rater agreement on 161 of the 191 comparisons (84%) ranging from a low of 67% on wheelchair to a high of 100% on eating. On the items most crucial for family decision making (transferring, walking and stairs) the agreement rates were 90%, 84% and 88% respectively.

Attitude and Role Inventories

Two of the three attitude and role inventories used in the project are published and copyrighted. Figures concerning their reliability and validity can be obtained from their authors or publishers, Hurvits (1961 - family)* and Suinn (1966).** The third instrument is the Measurement of Goal Agreement (Poulson, 1966 - family). Further information about this is available in a doctoral dissertation.***

The adaptations we made to fit the special conditions of stroke families should have reliability about equal to the original instruments since the changes are so slight, usually a pronoun change.

---

* Western Psychological Services, Box 775, Beverly Hills, California.

** Richard M. Suinn, Ph.D., Dept. of Psychology, Colorado State University, Fort Collins, Colorado 80521

*** Poulson, Jenniev, Factor Influence in Goal Agreement Between Husbands and Wives, University Microfilm Library Services, P.O. Box 1436, Ann Arbor, Michigan.

Excerpts from Content Analysis of Counseling Records

This section presents excerpts from the content analysis of records of the counseling carried on with experimental patients. The material is arranged in the same categories as the briefer illustrations presented in Chapter 3, Volume I. Additional selections are presented to give a more complete picture of problems faced by stroke patients and their families, solutions found, and what part the counselor played in these. All of this material, of course, reflects the perceptions of the counselor.

For experienced medical social workers and rehabilitation counselors, there is nothing new in the materials presented in this section. We think, however, that it may be of value for social work and counseling students as well as established members of the other rehabilitation professions who may not be thoroughly familiar with the social-psychological dimensions of the stroke situation and what the counselor does about it.

Patient

Positive Changes in Patient Behavior and/or Attitude

The patient made an effort to control the irritability he had developed toward his son because of the stroke and the original good relationship began to redevelop because of the patient's effort.

* * *

The counselor referred the patient for occupational evaluation testing. He scored high in mechanics and aesthetic skills, and it was recommended that he take job training in the field of photography. Mr. Z appears very happy with the prospect of job training in photography. His outlook is much improved and he feels that now there is hope for the future.

* * *

The patient has decided to go back to work at his old firm doing a job that requires less work with decreased salary. This will help allay the financial difficulties that the family has run into.

* * *

The patient has improved steadily and she reports that she is more content at home now. She is able to fix dinner for her husband and can also make pancakes.

* * *

Mrs. R.verbalizes a good acceptance of,and no bitterness about, her illness. She feels it could have been a lot worse and she is optimistic about her chances for complete recovery. She does exercises as prescribed for one and one-half hours daily and accomplishes her household duties.

* * *

Deteriorating Changes in Patient Behavior and/or Attitude

Mrs. N does not want to stay in the nursing home, but wants to return to her own home. She was originally depressed by her assignment to the infirmary. Her own condition, coupled with her being surrounded by people who were quite ill, reminded her constantly of her now lost independence of having and living in her own home. She evidently regarded **the** nursing home as a kind of come down in status.

* * *

The patient told tales of suicide or murder in the neighborhood suggesting depression and a rather morbid state of mind.

* * *

This vindictive man takes no pleasure out of life and makes sure that no one else does either, particularly his wife. Avocational suggesiions seem fruitless. He believed that his arm and hand would return to normal. The fact that they have not and probably will not has depressed him greatly.

* * *

. . . pre-stroke interest in many things, now only sits. He likes to play sheepshead but speech problems prevent him.

* * *

. . . inability to communicate on any level except basic noise sounds has caused her to become anxious and agitated.

* * *

. . . depressed and tense. The stroke has accentuated her dependency. Seeking divorce - thinks husband doesn't care for her - husband had a **heart** attack - may be afraid of dying.

* * *

Patient cried easily when discussing routine family matters. Seems passive, docile, and generally depressed.

* * *

Mrs. C is depressed, feels alone and rejected, and is seeking divorce because of her husband's domination and criticism.

Mr. W is very passive - expects his wife to handle all aspects of their life.

* * *

Deteriorating Changes in Patient Behavior and/or Attitude - Continued

Patient is preoccupied and distracted, his judgement impaired. Cooperative, but has difficulty paying attention. Compelled to center conversation around small, concrete details. Ignores paralysis of left side.

* * *

Unrealistic Patient Attitudes, n.e.c.

Mr. M hasn't yet realized their situation, apparently because he does not want to face the fact that their income is severely reduced. He can't understand why his wife has trouble making ends meet, and blames her for mismanagement of funds rather than understanding that they have less than half of their previous income available.

* * *

Mr. J seems to be unable to accept the limitations of his disability and compares this present situation to his previous abilities. At the present, he does not seem able to accept the possibllity of returning to a more limited form of work. This attitude, in part, may be due to his conception of a man's job as being physical and woman's work being less physical.

* * *

The patient feels that she has been neglected by her husband's family and cannot understand their attitude for that. It is the counselor's impression that if a little more were known about these things, Mrs. G would realize that there were good reasons for the way in which they were done.

* * *

The patient exhibits an unrealistic attitude in the goals he sets for himself. Even though his recovery is to the point where he has returned to work for five hours a day, the patient feels that this is not good enough and he is greatly dissatisfied.

* * *

The patient has placed all her psychological problems as being caused by her bad arm and leg. It does appear she does not want to face up to her problems..

* * *

The patient's only function in the family at this time seems to be that of housewife, and, while the counselor was at home, she seemed to stress this function, cleaning somewhat compulsively.

* * *

Unrealistic Patient Attitudes, n.e.c. - Continued

The patient just sits around all day,is bored and irritated. There is a definite personality change; he is depressed and unrealistic about his hopes for recovery. He expects miracles in the way of rehabilitation.

* * *

Patients' Post-Stroke Avocational Activities

Mr. H spends a great deal of time watching television with his wife and son. He also has a card club that he belongs to, the members being all of Slavic descent. He enjoys this activity very much because it gives him a chance to converse in his native tongue - Yugoslavian.

* * *

The patient enjoys drinking and socializing with friends, loves to play cards and has participated in the Wheelers and Dealers Club at Curative Also, driving a car gives the patient much satisfaction. The patient is aware of his ability to interact well with others, and has received excellent reports from the E and A supervisor.

* * *

The R's are quite active in the Baptist Church and maintain quite a number of social ties through the church. Since they have no car and the patient is rather big to get around in a wheelchair, they do not go out much, but do entertain in the home. Mr. R loves to fish, although he does not get much of a chance to do this anymore.

* * *

The patient has never placed much interest in outside activity or participated in any social organizations. She is a member of the Lutheran Church and attends services regularly.

* * *

The patient apparently has a good relationship with the upstairs neighbor and with a cousin who visits often. The neighbor escorts her around the neighborhood and the cousin has promised to take her out in the car "when the weather turns nice."

* * *

The patient has obtained permission of her landlord to work on the grounds around her apartment building - planting shrubs and other plants primarily.

* * *

Patient - Continued

Patients' Post-Stroke Avocational Activities - Continued

The patient states that she likes to sew and do needlework, and the patient's daughter mentioned that she bought some embroidery fabric and material for her aunt. Currently, the patient also practices shorthand and reads newspapers. She enjoys taking walks and can go two or three blocks unaided.

* * *

Currently, all the patient does is take walks or go shopping with his brother, sister, or both. He does not do any work around the house nor does it appear that he is encouraged to do so by the family.

* * *

Spouse

Dependency on Spouse

The patient has made great advances since his stroke. He does quite a bit of the housework while his wife works. This, however, is not what the patient wants. He does not like being dependent on his wife for the income she brings home, and he feels that he has lost much of his manhood because of it.

* * *

The patient is almost completely dependent upon the spouse. He does most of the housecleaning, shopping, etc. The patient can only be understood by the spouse which adds to the dependency factor.

* * *

The relationship between the patient and spouse here is very poor. The spouse prefers to remain retired even though he is capable of working, while the patient wants to work but is impeded by the spouse. Tension has developed between the two, and the patient is now considering divorce. There is apparently no great feeling of dependency on the part of the patient towards the spouse.

* * *

The patient has allowed all the authority in the house to fall on the spouse. All the financial matters, etc., are handled by the spouse. The patient appears content to sit around and do nothing.

* * *

Dependency on Spouse - Continued

Mr. K has complete care of Mrs. K and the house. He has taken over the laundry, ironing, baking and canning and is proud of the job he has done.

* * *

Mrs. R, the patient, always did all the household management and was the dominant person in all family decisions until her health failed. Mr. R has found it hard to take over and, although he does not complain, he obviously feels burdened by the household duties, his restricted life, and the need to help Mrs. R with personal care.

* * *

Evidence of Spouse Resentment

The patient has been uncooperative and does nothing to help Mrs. M around the house. He will not do what he considers "woman's work". Instead of helping he constantly criticizes and yells about Mrs. M's homemaking, management of finances, etc., and doesn't seem to appreciate what his wife tries to do. Therefore, Mrs. M resents this attitude. She verbally expressed this resentment once when she said, "I just wish he'd give me a little credit."

* * *

Mr. O seems somewhat resentful of his wife because in his opinion she is not working hard enough towards her recovery. Mr. O compares his wife's efforts to those of this father, who also had a stroke. Apparently his father worked very hard at recovery and did very well. According to Mr. O, Mrs. O's doctor said he considers Mrs. O lazy in her efforts to get back certain functions. Mr. O, too, feels that his wife is being lazy.

* * *

The counselor feels that the spouse, due to the wife's stroke, has developed an unconscious resentment toward her which is exhibited in rather subtle actions and innuendos. Mr. G wonders why "this terrible thing had to happen to them."

* * *

The marital difficulties referred to in the earlier reports have finally resulted in a separation and filing of divorce papers. The patient complained about the lack of help given to her by her husband in particular, . . . (saying) "My husband has no pity whatsoever for anybody anymore."

* * *

Evidence of Spouse Resentment - Continued

According to the patient, his wife is very possessive of her time and discourages him from any participation in household chores. She is impatient with his attempts to do things, even for himself.

* * *

Adjustment of Spouse to Patient, n.e.c.

This seems to be a stable family where there is a great deal of mutual respect and admiration. There is a strong sense of loyalty and responsibility for each other's welfare, and appreciation of each other's problems and emotional needs. The counselor feels that this family has made a very good adjustment to the stroke.

* * *

The husband appears to be very dominating toward the patient, does not let her talk, "helps" her often, etc. She appears to be a passive-agressive type, possibly using her illness as a means of keeping him attached to her.

* * *

The wife was perceptive and accepting of her husbnad's situation. She generally maintained self-control in front of her husband, and was able to scold him into doing things for himself. She realized the loss he felt at not being able to practice his profession (the patient is an M.D.).

* * *

Both the C's seem to have a resigned attitude toward their illnesses, in particular towards Mr. C's stroke. They have lived with the problem so long that this last illness did not disturb their lives as much as it might have. For many years Mrs. C has been the breadwinner. They are both accustomed to their respective roles.

* * *

The W's seem to have established a basically sound relationship. There is a real bond of affection between the two. At this time, however, there are frustrations and hostilities between the two. Both feel their confinement is bad and makes them irritable with one another.

* * *

Spouse - Continued

Adjustment of Spouse to Patient, n.e.c. - Continued

The patient's wife stated her own attitude had become more tolerant, that she no longer cried and became upset when he became frustrated and swore at her. She just laughed at him and threatened to wash out his mouth with soap, and then he just laughed, too.

* * *

Since the enrollment of Mr. H into the E and A program at Curative Workshop (as recommended by the counselor), Mrs. H has made a much better adjustment to the stroke. It gives her more free time and thus she can relax a bit more.

* * *

In general, the spouse has made a good adjustment to her husband's stroke. She has managed to maintain the household and help with the rehabilitation of the patient at the same time with not too much strain.

* * *

* * *

Children

Type of Help Planned and Given Patient and Spouse by Children

There are three children: one daughter offers financial aid by making a weekly contribution, another daughter is paying for her own education, and the son is helping out with chores around the house.

* * *

The daughter is a registered nurse and has helped to get the patient to rehabilitate himself.

* * *

The patient currently lives with her married daughter, her son-in-law, and five grandchildren, ages twelve to twenty-one. The daughter appears to be a very capable person and both she and her husband are very helpful and protective of the patient.

* * *

The patient says her daughters are very helpful to her. Since she has not been able to resume all the home activitites, her daughters, under her direction, do a great deal of cooking and food preparation.

* * *

Children - Continued

Type of Help Planned and Given Patient and Spouse by Children - Continued

All the D children live in the Milwaukee area and there is a lot of family visiting. A son takes Mr. D to the parish activities and Mr. D is looking forward to an evening of cards with this group soon. A son-in-law brings Mr. D to the workshop for therapy now that Mrs. D has returned to work.

* * *

Mrs. P is not much for housekeeping, and never has been. Her daughter and son have always had household chores to do and therefore there has been no considerable change since pre-stroke activities.

* * *

There is considerable family visiting and mutual cooperation. Mrs. F (patient's daughter) assists the S's in many ways - shopping, laundry, driving Mrs. S to Curative Workshop.

* * *

Patient - Family

Solutions to Problems Reached by Patients and Families

The house that the patient lives in was very crowded because the patient moved in. The family has planned to add on another room for Mrs. T to live in, thus alleviating the problem of crowded space and giving Mrs. T the security of living there on a permanent basis.

* * *

Since the patient is unable or unwilling to help herself or care for herself, the family of the patient has let the woman move into their home. While this is an inconvenience to the family, they are willing to accept it, knowing it is for the good of the patient.

* * *

Financial problems in this family are being resolved by everyone chipping into the kitty - each offers a little financial aid, even children. Also, the patient is planning to return to his old job.

* * *

The patient's niece is a rather domineering woman who is determined that the patient be as independent as possible. The niece feels that her aunt is capable of doing more around the house than she does (which is practically nothing). The niece mentioned that she threatened the aunt with the possibility of a nursing home unless the patient became more independent.

* * *

Solutions to Problems Reached by Patients and Families - Continued

Although the N's have no children of their own, they are quite close to their families and see them often. One niece in particular visits often and helps Mr. N around the house.

* * *

The sister, age 59, was employed as a supervisor of inventory at a department store. She is presently on leave of absence in order to care for her sister. In general, this seems to be a highly supportive family.

* * *

According to Home Service, the patient has always been rather slow mentally and the family has a tendency to help the patient too much, i.e., they do not try to get the patient to do things for himself. Apparently it is easier for them to do things for the patient than to encourage him to do things for himself.

* * *

Moving plans of Patient and Spouse

Move from	Move to	Why
Son's home	Private apartment	Mr. L wants to have the chance to socialize with his friends. Also, Mr. L is aware that his son resents his living with him and his family. (This desire to move out has never been fulfilled. At the time of the followup, Mr. L was still residing at his son's home.)
Son's home	Nursing home	Mr. W's family feels that the patient is creating too much tension in the home. They think that if he is no longer living with them their marital problems will end.
Own home	Nursing home	The patient's family feels that it is best for her to be in a place where they know she is being cared for.

Patient - Family - Continued

Moving Plans of Patient and Spouse - Continued

Move from	Move to	Why
Present home	Larger flat	More room and better accomodations for the patient, her daughter and son-in-law, and grandchildren. Evidently the living arrangement is considered a permanent one by all parties concerned.
Daughter's home	A new home the daughter and son-in-law are buying	Their old house has been marked for demolition by the housing authority.

Counselor

Instances of Counseling

The counselor has tried to counteract the patient's depression by emphasizing the positive achievements she has made: climbing stairs, working in the garden, etc.

* * *

The counselor suggested that the patient educate her girls to assume an even greater share of household chores than they already have, thereby giving the patient more time to rest and relax.

* * *

The counselor helped Mr. B to better understand the term "conversion hysteria". Previously, the patient took offense at this classification. Mr. B had a misconception of what the term meant. After discussion with the counselor, he realized that this is not a voluntary occurrence. The patient is now in a much better position to understand the illness and to have a more realistic approach to it.

* * *

The counselor has attempted to give a more realistic outlook of a stroke to the patient. He feels that he should be able to return to his previous self - completely. He becomes depressed and agitated when he feels that he is not accomplishing his pre-stroke standards. She (the counselor) has pointed out that his recovery to date has been great and that realistically he will not be completely able to do all he had been doing before the stroke. Hopefully, from this point, the patient will be able to continue his rehabilitation and not suffer as many of the drawbacks of depression.

* * *

Instances of Counseling - Continued

Due to resentment of patient's disabilities on the part of the younger sister, the counselor suggested a discussion with the sister to explain the nature of a stroke and its effects.

* * *

The counselor helped to give Mrs. H a better perspective of the situation the family is in. Previously, Mrs. H would become very depressed over the problem. The counselor pointed out to her that they have always been a family that has been able to adapt to any situation and that this situation could be no different. This seemed to console Mrs. H and to bring her out of her depressed state.

* * *

Advice Given Patient and Spouse by Counselor

Mrs. M was greatly opposed to allowing her daughter to go away to college. As a result, there was much turmoil in the household. The counselor advised the patient to allow the daughter to go away to school. This advice was taken and the patient now realizes that the decision was the right one, as the turmoil has diminished and the family situation has greatly improved.

* * *

The counselor offered the patient advice on how to obtain another job, as he was unable to resume his old position. The counselor also raised the possibility of referral to the DVR, who performed OEL testing. The patient has since been able to obtain employment.

* * *

The counselor offered a more realistic approach to rehabilitation of the patient. The patient and his spouse were counseled in ways to resolve some of the family difficulties that existed, especially between the patient and his teen-age son. The counselor also discussed finances and avocational activities with the patient and his spouse.

* * *

The counselor aided the T's in their financial planning. They have had some difficulty in getting things straightened out (including insurance, medicare, etc.) and apparently the counselor was able to help them very much in this area.

* * *

The counselor offered the couple much advice on how and whom to contact to find employment. Also, she helped them with managing a budget and with obtaining needed medical devices, including glasses.

* * *

Advice Given Patient and Spouse by Counselor - Continued

The counselor advised the couple that the patient should get back to work as soon as the doctor gave his approval. The counselor suggested that the patient's wife get him involved in more activities and to get him out of the house more.

* * *

Instances of Counselor Case Management (Referral Expediting, Etc.)

The counselor suggested that the patient could receive sewing help from O.T. Also, counselor arranged for Ambucab transportation on Fridays since the patient has no convenient way of coming to workshop on those days.

* * *

The counselor informed the patient of activities at Washington Park, and told her about the bookmobile that stops in her neighborhood. Counselor tried to ascertain what activities local church groups might sponsor in the neighborhood.

* * *

The counselor suggested referral to the Curative Workshop Activities program. The activity might help his (patient's) attitude at home, for the benefit of both patient and wife, the counselor reasoned.

* * *

The counselor referred Mr. D to the Activities Program at the Curative Workshop. He had hoped this would serve as a transition period, helping the patient regain his confidence in his abilities and also to help him accept a less physical form of work.

* * *

Mrs. N derives much strength from her religion. An effort was successfully made by the counselor to inform her pastor of her situation, and he responded well. It was felt that the pastor could encourage Mrs. N's participation in church or neighborhood groups, and help alleviate her fears of living alone, and of death.

* * *

Ways in Which Counselor Helped
Other Than with Counseling, Advice, or Case Management

There is one minor problem within the family that the counselor has helped the K's with. This is the family concern about what their son, 17, should do after high school. The counselor arranged to have the State Employment Service provide the boy with vocational counseling, a gesture which the K's appreciated very much.

* * *

The counselor has helped considerably in easing the tension in the M's household. First, his advice to let the daughter go to college has helped greatly. Second, his advice and counseling concerning the patient's ability to write and type has helped her to become involved in the Mariner's Drum and Bugle Corps again. This involvement has added confidence to the patient and this has carried over into other aspects of her recovery.

* * *

The counselor has given Mr. H a better perspective of his illness by discussing with the patient the nature of the ailment. Hopefully, this will give the patient a more realistic appraisal of what he is confronting and also, ways to deal with the illness.

* * *

The counselor eased the tension considerably in the X household by bringing the problems to the surface where they could be examined, instead of being hidden behind an unfounded rationale (that the patient was the root cause for all that was bad in the X household).

* * *

The patient was afraid and upset by the psychological testing. The counselor therefore explained some of the programs to her, explaining that it was completely voluntary on her part, that counselors do not have any authority, and do not wish to do anything she does not wish to do. The counselor also explained that all information is confidential. This seemed to relieve the patient somewhat.

* * *

It was suggested that the patient (himself an M.D.) be approached as a "consultant" on the project rather than as someone in need of help himself. This would be in deference to his status as a professional man and a physician. He could be asked what, according to his experience, he felt could or should be done for stroke patients in general.

* * *

Subjects Discussed by Counselor, n.e.c.

The counselor discussed with Miss G her feelings about the program at the Curative Workshop in order to find out her opinion of it. He then inquired about the patient's financial situation, job history, family structure, living situation and avocational activities. After this information was obtained, the counselor spent some time finding out general information about Miss G's life pattern - complaints, etc.

* * *

The counselor discussed the relationship between Mr. and Mrs. Y. He explored with them the possibility of the patient's entering a home. He tried to make clear the need for a better understanding of the limitations that the patient has. The counselor then discussed budget planning and new avocational activities for all members of the family.

* * *

The counselor inquired about the relationship between the patient and her children. The counselor saw that the patient had a particular need to have companionship, and discussed ways that this could be accomplished. He also talked about financial matters and how to deal with them, along with the patient's need for more avocational activities.

* * *

The counselor discussed some concrete methods of dealing with the patient's problems, including her need for physical care and emotional support. He inquired about Mrs. M's financial needs and future employment possibilities. The counselor talked about the impact of the patient's illness on the rest of the family - especially the family's vocational and educational goals. He offered assistance in securing financial aid for the educational goals, if necessary.

* * *

The counselor advised the family with the aim of redistributing expressive roles in the family, helping members of the family to adapt to role changes necessitated by the facts of the patient's new condition.

* * *

Contact with Agencies

What Physician and Therapists Told the Patient and Spouse to Do

Advice Given	Type of Person	Following Instructions Yes	No
Talk as much as possible	Speech therapist	X	
Reduce weight through dieting; exercise through walking	Family doctor and Physical therapist	X	
Place the patient in a nursing home	Doctor		X
Become more active - motivate more	Counselor		X
Return to work.	Counselor	X	
Exercises for functional ability and endurance in walking	Occupational therapist Physical therapist	X	
Exercises to improve gait and transfers, and to increase function in right extremities.	Physical therapist	X	
Homemaker training	Occupational therapist		X
Supportive counseling; Group sessions	Counselor	X	
Independence in self-care and ambulation (exercises for)	Physical therapist Occupational therapist		X
Activities to increase standing tolerance and to maintain passive ROM of right upper extremity	Occupational therapist	X	

Mrs. M said she called the counselor because we had tried to do so much, and the Workshop had been so wonderful to them. She will keep in touch with us.

* * *

At the time of the followup, Mr. J expressed happiness over his position at the Activities Program and thought only good things about Curative Workshop and what they had done for him.

* * *

The R's held the Curative Workshop in high esteem. They feel that the Workshop has helped them greatly in coping with their problems: medically, financially and emotionally.

* * *

The patient enjoys coming to the Curative Workshop. She apparently views her visits as a means of getting out of the house. It almost seems as if her only pleasure is derived out of going to the Workshop.

* * *

The son said the patient is rather discouraged by what she has been doing at the Workshop. She feels that since she is able to do the housework now, it is a waste of time, money and effort for her to work in the Homemaker's Lab.

* * *

The patient expressed his dissatisfaction concerning the way his examination by the doctor had been handled. He did not see the necessity for the exam since his own doctor . . . was familiar with his condition and had made the referral. The patient's chief complaint was of the five therapists at his examination, which embarrassed and humiliated him.

* * *

Mr. R feels that his wife has improved in many functions, including communication, since coming to the Workshop and wants her to continue.

* * *

The patient intends to keep himself as busy as possible, and already both he and his wife feel he has made tremendous progress since coming to Curative.

* * *

Other Agencies Patient or Family Had Contacted and/or Received Help From

Agency Contacted	Kind of Help Received
Catholic Social Service	Mr. P sent his daughter to this agency to help her work out the problem that existed between the daughter and the patient.
Veterans' Administration	Disability compensation and extensive medical aid.
The Department of Public Welfare	Patient and spouse have been able to obtain Title 19 coverage for two dependent grandchildren.
The Masons	Family received information on possibility of putting the patient in one of the organization's rest and retirement homes.
DVR	This agency ran tests on the patient and was instrumental in finding work for him.
Medicare	This helped patient and family obtain much needed equipment that they normally would not be able to obtain.
Visiting Nurses Assn.	Once a week a visiting nurse comes to see patient and give him a bath - he is unable to do so himself.

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EDUCATING STROKE PATIENT FAMILIES

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CURATIVE WORKSHOP OF MILWAUKEE
UNIVERSITY OF WISCONSIN

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EDUCATING STROKE PATIENT FAMILIES

Final Report

VOLUME III

Robert P. Overs, Ph.D. and John R. Healy

July, 1971

Research Department

CURATIVE WORKSHOP OF MILWAUKEE

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The MILWAUKEE MEDIA FOR REHABILITATION REPORTS is designed to make available rehabilitation research information which is not easily disseminated through the usual publication channels. Some of these reports will be concerned with methodological notes and techniques which are too specific in interest to appear in regular journal publications.

Others, suitable for journal publication, will be published in the MILWAUKEE MEDIA when it appears desirable to avoid the current publication lag.

A third type of material to be published will be studies geographically related to Milwaukee and Wisconsin which, while important to that area, may have limited significance in other parts of the country.

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This Report is published in three volumes, of which this is Volume III.

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TABLE OF CONTENTS

Section Title	Page
Introduction to Volume III	4
Annotated Bibliography of Movies on or Related to Strokes	5
Purposes and Procedure	5
Four Films Considered as Having the Most Potential for Educating Stroke Families	5
Annotated Listings of Twenty-Two Other Films Reviewed (Alphabetical-by Title)	6
Annotated Bibliography	10
Aging, Geriatrics and Retirement	10
Aphasia	13
General	14
Marriage and the Family	17
Stroke - Cerebrovascular Disease	25
Bibliography	31
Aging, Geriatrics and Retirement	31
Aphasia	33
General	34
Marriage and the Family	41
Stroke - Cerebrovascular Disease	47
Author Index	54
Project Report Index	59

INTRODUCTION TO VOLUME III

Volume III is the third volume of the final report of a project entitled "Educating Stroke Patients Families". In Volume I and II are reported the design, methodology and outcome of a four year project to determine the effect of intensive counseling and/or casework services in maintaining and possibly improving patient gains after the completion of a rehabilitation program.

An intensive followup of patients and their families recorded significant information about patterns of housing status, financial status, employment history, remaining patient capacity in activities of daily living, role changes in activities of daily living, patient knowledge and use of community resources, patient social contacts, patients' evaluations of their stroke experience, and finally patients' evaluations of the rehabilitation program.

Presented first in Volume III is an annotated bibliography of 26 movies about or related to stroke which were written after studying the films.

The next section is an annotated bibliography of stroke related publications. These annotations are approximately 125 words in length and are designed to give the reader a quick survey of significant related studies.

A bibliography with 316 entries follows. The annotated selections are also listed in the bibliography with the word "Annotated" following the listing. Both the annotated section and the bibliography are divided into the same five major sections. These are:

Full Title	Abbreviations used in the Narrative
Aging, Geriatrics and Retirement	Aging
Aphasia	Aphasia
General	General
Marriage and the Family	Family
Stroke-Cerebral Vascular Disease	Stroke

References in the narrative (Volumes I and II), in addition to listing the usual author and year, are followed by the abbreviation for the biblographic section in which the item is listed. An author index in Volume III cites the page(s) on which references to a given author may be found in the annotations and bibliography.

Finally, there are two indexes for this volume: an RSA-VRA-OVR Project Index, and an author index.

ANNOTATED BIBLIOGRAPHY OF MOVIES ON OR RELATED TO STROKES

Purpose and Procedure

Our purpose in reviewing these films was to select those that could be shown to a patient-spouse audience. We wanted to do this for two reasons: first, to present the families with sufficient factual information to understand the causes and consequences of a stroke; and secondly, to provide the framework for group discussions of the problems of stroke families. We wanted films which would address themselves to one or more of the following questions:

1. What is a stroke-medically, what happens, where and why?
2. What are the consequences - physically, psychologically and socially for both the patient and the family?
3. What are the solutions - to these problems caused by stroke?

In evaluating the films we used the following general criteria:

1. Technical accuracy - are the facts, examples, procedures, etc. correct and up-to-date.
2. Intelligibility - can the film be understood by the lay audiences.
3. Realism - does the film present material in such a way as to allow our proposed patient-spouse audience to identify with it; or are scenes and situations too atypical or too dated to be of interest.
4. Appropriateness - is the material suitable for patient-spouse audiences or is it too "loaded" or emotionally charged.

The actual reviewing was done by the Project staff and Agency service personnel. By and large, most of the 26 films reviewed, fell short of our expectations. They were either too technical or too melodramatic. Few attempted to deal with psycho-social problems at all, and most of those which did were not very realistic. However, there were four which were far superior to the others and these are described separately. The other twenty-two are in an annotated listing by alphabetical order of the title.

Four Films Considered as Having the Most Potential for Educating Stroke Families

Strokes, American Heart Association, 1957, Produced by Churchill-Wexler, Time: 6 minutes.

A short, concise, non-technical description of the internal causes of a stroke. Uses animated drawings to show the mechanics of clotting, hemorrhaging, hardening of the arteries and how these result in strokes. It explains the process of "spontaneous" recovery and one possible criticism is that perhaps this is overdone and may give rise to false optimism.

Cerebral Vascular Disease: Challenge of Management; 39 minutes.
Second Chance; 28 minutes.
both American Heart Association films, produced by George C. Stoney Associates 1969.

Both these films deal with a 63 year old fireman who suffers a stroke. Second Chance is the story as seen by the patient himself and his family; CVD: Challenge of Management uses much the same film footage but presents it more objectively, with the material divided into five distinct phases, and a narrator explaining the peculiar problems of each stage.

They both make a great effort to explore the psycho-social aspects of strokes and could be used together, or separately, as a basis for group discussions. Some of the problems presented, and ways this family met them, are as follows:

a) inappropriate response - i.e. crying instead of laughing
b) depression and apathy of patient at slowness of recovery
c) feelings of being "tied down" by those caring for patient
d) excessive "babying" of patient
e) need for patient to have meaningful work in household

Our only negative comment on this film is that the recovery of the patient seemed exceptionally dramatic. This might raise unrealistic hopes in the audience.

Inner World of Aphasia, Psychology Exploration Films, 1600 LaLana Avenue, Berkeley, California 94709; Produced by Leonard Pearson, 1968.

An extremely well-done and highly controversial film which utilizes modern cinematic techniques (flashbacks, split screen, voice-over, etc) to show what the aphasic, brain-damaged, patient actually sees and hears. Shows how careless and thoughtless professionals can contribute to patient's critical image of his new self. Would seem to be almost "required" viewing for all rehabilitation people, from clerical staff to consulting physicians. Most of the professional staff felt that this film is not suitable for patient-spouse audiences because of the highly negative view of professionals it gives.

Annotated Listings of Twenty-Two Other Film Reviewed (Alphabetical- by Title)

Candidate for Stroke American Medical Association, 1966.

Evaluation: Story of a stroke as seen through a patient's eyes. The audience never sees him. It sees only what he sees. The film illustrates some of the many tests he must undergo, and the slow, patient steps he must take on his way back to recovery. It points out the importance of recognizing the "warning signs" which often precede a major stroke, and it dramatically underscores the simple but vital precautions anyone can take today to reduce his or her risk of suffering a stroke or heart attack. Does not really go into the psychological after-effects.

Cerebral Vascular Disease: The Challenge of Diagnosis American Heart Association Produced by Churchill-Wexler Film Productions, 1961. Time: 30 minutes.

Evaluation: Stresses the importance of accurate differential diagnosis and uses 3 case histories to illustrate different procedures to diagnose CVD. Stresses importance of premonitory signs. Doesn't deal with strokes. Not suitable for spouse audience.

Disorders of Gait Center for Mass Communications, Ernst Herz. Tracy J. Putnam, U.S.A. Time: 40 minutes
Facial Palsy Center for Mass Communications, Ernst Herz. Tracy J. Putnam, U.S.A. 1948, Time: 30 minutes.

Evaluation: Both were very technical and strictly for professional viewing. Very old films.

Highlights of Heart Research Produced by U.S. Public Health Service in cooperation with John Hopkins Medical School, Holter Research Foundation, Michael Reese Hospital and Medical Center, Baylor University College of Medicine, 1961. Time: 8 minutes.

Evaluation: A 5-part newsreel showing highlights of research including stroke surgery.

Introduction to Aphasia U.S. Veterans Administration, Produced by Churchill-Wexler Film Productions, U.S.A., 1950, Time: 30 minutes.

Evaluation: Very well done but highly technical description of what aphasia is and how it may affect the patient. This film would be useful to professionals or students. Shows examples of aphasic patients and their difficulties in communicating, and some problems peculiar to each type of aphasia. Shows how difficulties are identified and treated.

On Our Own March of Dimes

Evaluation: Focused mainly on polio disabilities. Demonstrated how disabled people adapt. Entails a re-learning process. Did not consider strokes.

Physical Diagnosis: Abnormalities in Gait Motion Picture Library. AMA, Gordon B. Myers, Fred J. Margolis and Muir Clapper, U.S.A., 1955, Time: 16 minutes.

Evaluation: Silent film. Demonstrated various unusual and abnormal gaits. Covers nothing in the realm of strokes.

Physical Diagnosis: Disorders of Motility Wayne State University, U.S.A., 1961, Time: 37 minutes.

Evaluation: Disabilities and background covered. Informative but consensus was that it was much too professional and clinical and covered little on strokes.

Prevention of Disability from Stroke American Heart Association, 1961, Produced by Health Film Associates correlated with booklet, STRIKE BACK AT STROKE, Time: 28 minutes.

Evaluation: The film is correlated with the booklet, STRIKE BACK AT STROKE. It demonstrates the therapeutic exercises in the booklet which were developed by experts in the field of medical tehabilitation therapy. The film stresses the point that recovery is possible through exercise prescribed by a physician

to mobilize each patient's fullest potential. Emphasizes the importance of a physician's direction. Deals with bed positioning, exercising of muscles and joints, etc. Brings family role into focus. The emphasis in the movie, however, is more on what needs to be done for and to the patient than on what he can do for himself and/or what the family should allow him to do for himself.

Proud Years

Evaluation: Filmed at old age home in New York. Emphasizes importance of activity for aged - shows the value of humor and fun type activities: games, horseplay. Patients are all old and multiply handicapped.

Heart Research News Produced by U.S. Public Health Service U.S.A., 1962, Time: 15 minutes.

Evaluation: On a very professional and technical level - shows recent developments in the field of heart research. Educational, but unsuitable for a patient audience.

Ready for Edna U.S. Public Health Service and National Educational TV and Radio Center. Produced by Center for Mass Communication of Columbia University Press, 1965, Time: 29 minutes.

Evaluation: Examines broad range of health services needed to promote and protect physical and mental health of the aged. The concern here is with the aging population, its needs, and the resources to meet them - more so than with strokes, although Edna does suffer a small stroke and recovers rather quickly. Also considers life expectancy from a historical perspective.

Social Adjustment of Aphasics U.S. Veterans Administration Produced by Churchill Wexler Film Productions, U.S.A., 1950, Time:26 minutes.

Evaluation: Excellent; shows all aspects of treatment: social, OT, PT, Speech. Opening scene is a group discussion where aphasics tell problems and how people can hurt while trying to help. Emphasizes how different therapies must coordinate treatment plans to goals.

Stroke --Early Restorative Measures in Your Hospital Illinois State Medical Society, Produced by Henry Ushijima for Calburn Associates, U.S.A., 1962, Time: 20 minutes.

Evaluation: Good, comprehensive coverage of the early practices for rehabilitation of stroke patients. Emphasizes that any interested person is capable of exercising and training patients. Emphasizes continually the possibility of almost complete recovery.

The Stroke Patient - Part 1 about 25 minutes

Evaluation: Concerned mostly with bedridden patients. How to position patient in bed, etc. Not really applicable to patient-spouse group.

The Stroke Patient - Part II about 25 minutes.

Evaluation: How to help the patient move about the house; transferring activities, stairs, and curb climbing. Emphasizes patient helping himself and stresses daily exercises - gives example.

The Stroke Patient - Part III about 25 minutes.

Evaluation: Deals with toileting and bathing, dressing and eating for wheelchair bound patients. Shows how these activities can be performed with assistance.

Take it Easy Time: 13 1/2 minutes.

Evaluation: How family can reduce strain on wife with heart disease. Did not stress personal initiative. Danger that after seeing this, family would expect "experts" to make time-motion studies for them rather than use their own imaginations.

Testing of Aphasics U.S. Veterans Administration, Produced by Churchill-Wexler Film Production U.S.A., 1950, Time:28 minutes.

Evaluation: Excellent but highly technical description of diagnostic testing and techniques used by professionals to determine the extent of speech impairment. Last half is not too technical and might be used for spouse audience.

The Center Way Ohio State University.

Evaluation: Soap opera story of a rehabilitation counselor who is leaving her job and her patient, Ben, and how he "came through". Wishy-washy.

20th Century Epidemic American and Wisconsin Heart Association
Time: 23 minutes.

Evaluation: A report on the diseases of the heart and blood vessels which describes the medical, social and economic aspects. The most serious cardiovascular threats to Americans are documented - heart attack, stroke, inborn heart defects, hypertensive disease and rheumatic heart disease. Emphasis on risk reduction.

ANNOTATED BIBLIOGRAPHY

AGING, GERIATRICS AND RETIREMENT

Buck, Pearl S., "Creativity and the Aging American", Psychosomatics, Vol. 8, No. 4, 1967, Pt. 1.

Loneliness need not be an entirely negative thing. To be lonely is to be independent, and there can be a good deal of satisfaction from being independent. The boredom of old age results from not using one's talents to the fullest. The community should attempt to utilize the talents of the aged and make the older people an indispensible part of the community.

Cowgill, Donald O., Toward a Sociological Theory of Aging Based upon Cross-Societal Observations.

The author tries to develop some generalizations concerning how the social aspects of aging vary systematically between cultures. Variations are related to "degree of modernization," as is the proportion of older people to the total population, and the degree to which older people are able to perform a useful role in society. The position of the aged is relative to the dominant values of the society. A society such as ours that emphasizes individual development and individualistic achievement, places the older person at a disadvantage. A Puritan emphasis on the value of work makes for lower status of the old who can no longer work.

Goodstein, Leonard D., "Personal Adjustment Factors and Retirement", Geriatrics, Vol. 17, January 1962, pp 41-45.

Work provides a means of making a living while at the same time it satisfies the basic psychological needs of the individual. Work confers on the worker status, prestige, personal independence, sense of identity, outlet for social interaction and takes up time. These same needs must still be fulfilled after retirement. At present, society is not doing its part in helping the retired find adequate substitutes for their work roles. Counseling and pre-retirement planning is indicated.

Goodstein, Leonard D., Problems in Counseling Older Disabled Persons", Journal of Rehabilitation, July-August 1962.

The advanced age and combined problems of the older client -- economic, social, medical and psychological -- present the counselor with many problems. Society does not provide a clear-cut role for the aged, and the older person himself has an essentially negative self-concept. Also the typical client-counselor relationship is reversed in that normally the counselor is looked upon as someone older, wiser, more experienced, etc. With the aged this is not necessarily the case, as the client is usually older and may resent having to ask a younger person for advice. For both client and counselor, child-parent relationships may be recalled and further complicate the problems.

Neugarten, Bernice L., Personality in Middle and Late Life, New York: Atherton Press, 1964.

This work describes eight studies bases on samples of normal adults aged forty to ninety. The focus of the first group of studies was on middle age and the variations that occur in life styles and psycho-social patterns of behavior with age, sex and social status. The second group focused on changes that occur over this time among the middle aged and older people. Where the focus was on the "intrapsychic" aspects of behavior, chronological age provies order in the data; however, when the focus is on the "socioadaptational" aspects, individual differences are relatively independent of age. The age-related differences that have emerged are based in the personality rather than in the social environment. The findings imply that increased interiority and increased eccentricity of behavior in the aged precede, rather than follow, a lessening of social interaction. Intrapsychic behavior may lie closer to biological determinants than to social and some changes in function may be more closely related to health than to age. The general direction of personality change from middle to old age seems to be one of increased inner orientation and separation from the environment.

Phillips, Bernard S., "A Role Theory Approach to Adjustment in Old Age", American Sociological Review.

The study explores the utility of a role theory framework for understanding the adjustment of the aged. It pays particular attention to the relationship between the individual's self-concepts and his social roles. The degree of adjustment is hypothesized to be inversely correlated with both the extent of individual's involvement in the world of fantasy and his self image as being old. Absentmindedness, day dreaming and thoughts of death constitute the operational definition of identification as old. Four role changes are considered: changes due to the death of a spouse; changes due to retirement; feeling that people treat you differently; reaching the age of 70. For each role change there was a greater incidence of maladjusted responses among those who identified themselves as old rather than as middle-aged.

United States Dept. of HEW, Working with Older People, Vol II: Biological, Psychological, and Sociological Aspects of Aging, April 1970.

One of a four volume series designed to aid people working with the aged. It begins with a concise "Overview" of current theories and research in each of the three aspects of aging, and follows with an "Extended Review" of each topic.

This volume divides the physiological causes of aging into two types: intrinsic (cell death, cellular or extra-cellular changes, molecular disorders, enzyme changes, tissure rearrangement and integrative changes); and extrinsic (temperature, mechanical forces, radiation, toxic substances, diet, social milieu and microbes), outlining possible ways to retard effects of time and environment.

The psychological effects of aging include changes in perceptual ability,

motor performance, memory and learning skills, and intellectual abilities. These all affect the ability to adapt to the environment, including the work environment. Possible changes in personality with their effects on mental health are suggested. The problems of chronic illness and the special psychological pressures of the terminal phase of life are examined.

Possible sociological implications of aging are put forth. Income maintenance, health care, living arrangements and use of leisure time will all be societal problems as the proportion of aged to the total population increases. The possibility of a subculture of aging, with its political implications, is suggested.

Wolff, K., "The Emotional Rehabilitation of Geriatric Patients", Journal of the American Geriatric Society, Vol 14, 1966, pp. 75-79.

Elderly patients can be restored to a "normal" life. Care must be taken not to confuse "normal" with the state of health at middle age. Normal is taken to be what the individual rates himself to be, despite the findings of the examining physician. Success should not be measured entirely by restoration of function. More important is restoration of self-esteem and independence. The advantages of a geriatric unit in facilitating rehabilitation are discussed. Opportunities for older patients to make contact with one another is most important. Medical and social aspects of the case must be considered together for this age group even more so than for any other.

Youmans, E. Grant, Older Rural Americans: A Sociological Perspective, University of Kentucky Press, Lexington, 1967.

The author attempts to describe the special problems facing the rural elderly in America. He gives statistical data contrasting the number and condition of the rural and the urban aged. Individual chapters include articles on work roles, family relationships, and community activities. The special problems of the rural minority group populations are treated separately in chapters on the American Indian, rural Spanish and rural Negro. Some of the general conclusions were that although disengagement from the work role can be less traumatic for the rural, lower income and housing, transportation and health problems combine to produce special difficulties.

Zung, William W., "Depression in the Normal Aged", Psychosomatics, Vol. 8, No.5, 1967.

This study is an attempt to measure the amount of depressive symptomatology present in normal subjects 65 years of age and older through use of a self-rating scale. The aged population rated themselves lower on the predominantly biological items and higher on the affective items. The baseline of depressive complaints is higher for older people. but depression among the aged tends to take a different form from that found in younger subjects. The elderly depressed patients are characterized by their state of apathy, disinterest in surroundings, lack of drive, inertness and gloominess. Guilt was a relatively unimportant factor with the elderly people, their depression was more related to feelings of inferiority and loss of self-esteem.

ANNOTATED BIBLIOGRAPHY

APHASIA

Buxbaum, Joan, "Effect of Nurturance on Wives' Appraisals of Their Marital Satisfaction and the Degree of Their Husbands' Aphasia", Journal of Consulting Psychology, Vol. 31, 1967, pp. 240-43.

This study investigates the relationship between a wife's need to give affection and her judgement of her husband's disability. The subjects were all wives of men with aphasia resulting from a stroke. The hypothesis that wives' nurturant needs were related to a positive bias in the perception of their husbands' speech impairments was supported, as was the hypothesis that high nurturance was associated with marital satisfaction. It may be that husbands respond more to nurturant wives so the wives were not necessarily distorting when they reported more communication from their husbands. The study points out the importance of taking into account the pattern of needs of family members if maximum functioning is to be obtained from the patient.

Derman, Sheila and Manaster, Albert, "Family Counseling with Relatives of Aphasic Patients at Schwab Rehabilitation Hospital", ASHA, Vol. 9, No. 5, May 1967.

The family group counseling for relatives of aphasic patients was started in an attempt to meet the needs of the relatives for factual information, reassurance and an outlet for feelings of guilt, frustration, etc. The desire for factual information seemed to be the foremost concern of the relatives. These sessions seemed to increase the rapport between the staff and family and the staff and patient. The program evolved into an open-end, continuing group with the "hard-core" members contributing much to the discussion. Eventually, the staff took a less directive, information-giving role and concentrated more on the feelings and dynamics which came forth in the sessions.

ANNOTATED BIBLIOGRAPHY

GENERAL

Barry, John R. and George H. Dunteman and Marvin W. Webb, "Personality and Motivation in Rehabilitation", Journal of Counseling Psychology, Vol. 15, No. 3, 1968, pp. 237-244.

Ninety male patients ranging in age from 21-65 (mean 45.7) were given a variety of psychological and personality inventories. One year after the test administration, they were rated according to motivation for recovery and return to work. Strong motivation for recovery and return to work was correlated with a favorable self-concept, small discrepancy between real and ideal self, intelligence, attitudes of social restraint and an interest in people.

Bell, Gerald D. and Phillips, Derek L., "Playing the Sick Role and Avoidance of Responsibility", Paper presented at the Sixth World Congress of Sociology.

Do individuals differ in their tendencies to avoid responsibilities under symptoms of illness and if so, what determines these differences? The authors hypothesized that more dependent individuals would be more likely to avoid responsibilities, but the association was not particularly strong. The data did indicate that the more one's wife expects the patient to avoid responsibility, the more he will do so, especially if the patient is dependent. The influence of co-workers is also revealed: the extent to which the reference group tolerates sick role behavior affects the degree to which the patient is likely to adopt it. However, co-workers' expectations and dependency were only slightly related. When the expectations of the wife and co-workers were opposite, it appeared that the more dependent men tended to follow their wives, while the more dominant followed their co-workers. Job satisfaction did not seem to bear an important influence on the inclination to avoid responsibilities.

Brown, Thomas S., Physical Activities, Attitudes, and Therapeutic Classification of Coronary Heart Patients, Institute of Behavioral Research, Texas Christian University, August 1968.

Seventeen married couples, where the husband had suffered a myocardial infarction, were asked to complete a questionnaire and interview to assess the differences in evaluations of the patient's situation among the patient, his wife, and his physician. The results suggest that the patients and wives are not always in agreement as to the nature of the adjustments that have to be made. The wife may be overprotective of the patient. There was a tendency for the wife to underestimate her husband's ability as compared to his own self-appraisal. There was also a greater tendency for the wife to underestimate the husband's ability compared to the physician, than for the patient to underestimate his own ability compared to the physician. For the more strenuous activities, both the patient and the wife feel the patient can do more than the doctor thinks he should. The study suggests that greater communication between patient and wife, and between family and physician is necessary.

Burdge, Rabel, "Levels of Occupational Prestige and Leisure Activity", Journal of Leisure Research, Vol. 1, No. 3, Summer, 1969, pp. 262-274.

This study investigated the relationship between patterns of leisure activities and level of occupational prestige as measured by the four level North-Hatt Occupational Prestige Scale. The respondents were 1,635 individuals, 18 years and over, from Allegheny County, Pennsylvania, which includes metropolitan Pittsburgh. Of the 82 different leisure activities studied, persons in the highest occupational level were most active in 57, people from Level II most active in 17. The data indicates that for almost every type of leisure activity, the majority of participants will come from the middle or upper classes. The author suggests that this may be because persons of the lower or working classes have limited education and experience; or it may mean that non-structured activity is more frequent in people at this level.

Cassel, John, "Social Science Theory as a Source of Hypothesis in Epidemiological Research", American Journal of Public Health, Vol. 54, September, 1964.

This study discusses the deficiency of a mono-etiological explanation of disease. Factors which are causal in one situation may in other circumstances be neutral or even beneficial. The potential relevance of the human as well as the physical environment in determining patterns of disease must be considered. The study points out that social and health scientists should work together to develop a conceptual scheme that will indicate which social and cultural processes are most relevant to health. Man must also recognize that those causes responsible for the onset of the condition may be different from those responsible for the lack of recovery. The importance of integration within a social group in preventing and facilitating recovery from disease is suggested.

Fey, William F., "Acceptance by Others and Its Relation to Acceptance of Self and Others: A Re-Evaluation", Journal of Abnormal and Social Psychology, Vol. 50, 1955, pp. 274-276.

It was hypothesized that acceptance by others is in part a function of the relationship between self-acceptance and acceptance of others. It was found that estimated and actual acceptability are independent of each other. A large difference between the acceptance of self and the acceptance of others, where the individual valued himself much more than he valued others, tended to imply rejection by others. The difficulties involved in unequivocally establishing or refuting the original hypothesis were discussed.

Nash, Marygold V., Independant Living, a Study of the Rehabilitation of Physically Handicapped Adults Living in Foster Homes.

Seventy-four disabled adults were placed in foster homes as an alternative to long-term hospitalization or unsatisfactory living conditions. Finding foster favilies was not a problem and slightly more than one-half of the patients were successful. Those disabled early in life and those more severely disabled were more successful in adjusting to independent living. Perhaps they had a more accurate perception of their ability and did not expect too much. The most important single factor, especially for males, seemed to be the ability to find some work.

Starkey, Pearl Davidoff, "Sick-Role Retention as a Factor in Nonrehabilitation", Journal of Counseling Psychology, 1967, Vol. 15, No. 1, pp. 75-79.

This study attempted to devise an abjective measure for use in determining those cardiac patients more likely to be non-rehabilitants for extra-cardiac reasons. Three variables were studied: sick role, aging and career patterns. In the population studied, non-rehabilitants could be distinguished from rehabilitants according to their significantly greater tendency to agree with statements describing themselves as disabled, and by a relatively unstable previous work pattern. There was also a general tendency for them to describe themselves as older. Since all men in the study were physically able to return to the work role, these differences indicate a conceptual framework within which extra-cardiac forces are influential.

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MARRIAGE AND THE FAMILY

Ballweg, John A., "Resolution of Conjugal Role Adjustment after Retirement", Journal of Marriage and the Family, Vol. 29, May 1967.

In this study the families with males over 65 were divided according to whether the men were working or retired. It appeared that the retired husbands did not embark on careers of leisure but assumed greater household responsibilities. The wives of retired husbands showed a corresponding decrease in performance of household tasks. The retired husbands did not share tasks with their wives, but assumed full responsibility for a select group of tasks, usually those more masculine or marginal in orientation. It appeared that the husband's retirement and assumption of household duties did not constitute a major disturbing force to self-conception of the wife.

Blood, Robert O. and Wolfe, Donald M., Husbands and Wives, New York: The Free Press, 1960

This book is the result of interviews with 731 Detroit wives and 178 farm wives. It describes the power structure of modern urban families by an examination of the decision making process and the relative participation of spouses in various household tasks. The findings are analyzed with respect to the age, race, religion, social class, education and income of the participating families.

In general the data supports the theory of a trend towards more equalitarian families. The decision making power of the husband seems to be greatest at the honeymoon stage and declines steadily as the couple gets older, with a slight reversal of this trend at the retirement period.

The pattern of performance of household duties seems to be "one of marked specialization". Sharing of tasks does not seem to be usual even after the retirement of the husband.

The Authors also explore other aspects of married life. Wives were asked to indicate the most valuable aspects as well as the sources of stress and conflict in their family. Companionship was their overwhelming choice and the most valuable aspect of marriage, while money and finances seemed to be the cause of most disagreements.

Brodsky, Carol M., "Medical Roles in Family Treatment", Psychosomatics, Vol. 8, No. 4, Part 1, 1967.

The family, as the basic unit of social organization, has the most influence on an individual's development, but also is the most accessible to therapeutic interventions. The different professions require specilized approaches to intervention in the family system. This paper attempts to provide a guideline for the physician. The differences in role relationships between the physician-family and the psychiatrist-family are outlined and their implications explored. Fundamental differences in role, scheduling pattern, and scope of relationship require the physician to be cautious in undertaking family psychotherapy. Such therapy should be "recommended" rather than prescribed, and be emphasized as

exploratory rather than curative. Perhaps the most effective role the physician or psychotherapist can perform is that of communications-facilitator. Differences in values represent the most serious threat to family stability and improved communication may be necessary for the family members to clarify their respective goals and values.

Centers, Richard, Raven, Bertram and Rodrigues, Arolodo, "Conjugal Power Structure: A Re-examination", American Sociological Review, Vol. 36, No. 2, April 1971.

Following the same basic format as Blood and Wolfe (1960) 776 husbands and wives in Los Angeles were interviewed. The questions centered on the relative power of husband and wife in certain decision making areas. The Blood and Wolfe study focused on eight areas somewhat weighted towards a male's sphere of influence. This study kept the original eight items but added six new ones to balance the list between traditionally male and traditionally female tasks. The results generally substantiate those of the earlier study. The power of the wife was somewhat greater because of the new items. Overall the power of the husband seems to decrease with age and length of marriage. A majority of the families could be described as equalitarian and companionship was rated as the most valuable aspect of marriage. There was a relationship between authoritarianism, measured by an adaptation of the Adorno F Scale and the exercise of power in marriage.

Christopherson, Victor A., Role Modifications of the Disabled Male with Implications for Counseling, Final report of VRA Project No. 755, University of Arizona, November 1963.

Problems of adjustment following disablement were defined in terms of role modification, and the counselor's role was perceived as facilitating the necessary modifications. Possible relationships among the variables of extent of disability, vocational status, family situation, self and other perception, and the ability to modify roles were examined. An accurate perception of the self and the nature of the disability facilitates role change. The extent of disability does not seem to be correlated with the assumption of new roles. A counselor could help a patient and the family to come to a more accurate perception of their situation and encourage needed shifts in role performance but the counselor must realize, reciprocal nature of any changes in role perception on the part of the patient and spouse.

Deutsch, Cynthia P. and Goldston, Judith A., "Family Factors in Home Adjustment of the Severely Disabled", Marriage and Family Living, Vol. XXII, No.4, November 1960.

The gap between role prescriptions and the ability to assume the role is important to home placement. Only the very unusual family can surmount major role reversals.

Family adjustment to the disabled member in the home varies according to a major variable: the family's perception of the patient as "sick" or as a responsibility versus a contributing family member. Out of this variable, distinct patterns arise: (1) patient-centered: the patient is regarded as "sick" and the entire family gives extra attention and consideration to this person; (2) patient-neglect: the physical needs of the patient may be met but he is ignored emotionally; (3) patient-adjustment: the patient is made to adjust to the normal family routine so that the family is not disrupted. The adult patient's own actions, and the degree and manner in which responsibilities are assumed, are important in determining the adjustment of the family.

Duckworth, Grace L., "A Project in Crisis Intervention", Social Casework, March 1967.

This was a description of a demonstration project, involving a part-time social worker, who was available for conference within 48 hours after the first contact by the client. Counseling focused on the crisis incident itself, and it was clearly indicated to the client that the number of interviews would be limited.

A crisis intervention approach makes heavy demands on the caseworker, who must diagnose quickly, adapt interviewing techniques to the client's particular problem, and make maximum use of outside resources. It is exhilarating since resistance can be overcome more quickly, as client and caseworker become mobilized. Setting limited short-term goals creates a feeling of optimism. In 48 out of the 51 cases, the brief service approach seemed applicable. Followup questionnaires indicated satisfaction with counseling procedures, and the number of interviews.

The theory that more people can be served through the crisis intervention method is borne out by the study. The project caseworker, working less than half the time, served 51 families during the five-and-a-half month period; this is about the same number she formerly served working full time with the same kind of caseload in a similar agency.

These results suggest that a few interviews, given at the onset of a crisis when the patient is in a heightened state of anxiety and receptivity to help, may be more beneficial to him than long term treatment given at a later time. Brief service, sharply tailored to the client's particular needs and limited to discussion of the immediate problem to be solved, may be all that is necessary if properly timed.

Dyer, William G., "Analyzing Marital Adjustment Using Role Theory", Marriage and Family Living, Vol 24, November 1962.

The problems of adjustment facing newlyweds, are considered from the standpoint of role analysis. All conflict appears to be the result of one person's behavior not meeting another's expectations or vice versa. Newlyweds are unsure of what is expected of them and are generally unused to continually interacting with another personality. To resolve conflicts arising from such misunderstanding may require difficult personal adjustments as one's behavior

and/or expectations are closely related to one's personality. Reduction of conflict may occur without the actual development of a congruent perception of roles: by a change in the situation (moving, changing jobs, having a baby, etc.) or by "agreeing-to-disagree".

Feldman, Marvin J., "Privacy and Conjoint Family Therapy", Family Process, Vol 6 March 1967.

There is no simple relationship between the degree of privacy and the kind and scope of disclosure in psychotherapy. Conjoint family therapy requires that relevant self knowledge be examined in interaction with those most concerned. This therapeutic approach could operate to sanction fewer restraints and greater disclosure in the family both in and out of therapy. The implications for mental health for alienated man are profound.

Another advantage of conjoint family therapy is that the therapist acts as agent for the family rather than one individual, and is not likely to encourage individual change to the detriment of the family as a unit.

Friedman, Alfred S., "The 'Well' Sibling in the 'Sick' Family: A Contradiction", The International Journal of Social Psychiatry, Congress Issue 1964, pp. 47-53.

Family members constitute a social system wherein each individual member contributes to the health or pathology of the system as a whole. "Well" family members interact with "sick"members and this interaction may be a contributing factor in the maladjustment of the sick person. Thus, therapy, to be effective, must deal with the system itself not individual members. The author suggests that all members of the nuclear family, thogether with any other relatives who share the household, be seen together. No family member should be excused or seen separately.

Heer, David M. "Husband and Wife Perceptions of Family Power Structure", Marriage and Family Living, Vol. XXIV, No. 1, February 1962.

In this study couples were interviewed jointly and asked which partner would finally decide in the sase of a disagreement. The extent of disparity in the perception of the power structure was analyzed for significance according to whether the family was middle or lower class, and the wife was working or not working. For the total sample the husbands' perceptions of the family power structure were significantly different from that of their wives. In general the husband tended to credit more influence to the wife than she did for herself. The author feels that it is unlikely that husbands would minimize their own influence so in such cases, the wife's influence is the more likely to be underestimated. The working class, working wife families tended to show more disparity than the other subgroups.

Hink, Douglas L. and Arnold, Mary F., "A Study of the Adjustment Techniques of Patients and Their Families to the Non-Medical Needs Resulting from Chronic Illness", Results of a Pilot Study supported by the American Heart Association in California.

The families of five middle-aged, middle-income former heart patients were interviewed regarding problems resulting from illness. Lack of information about the consequences of the attack had led families to respond inappropriately. Community Service Organizations could fill this information gap--prepare brochures, playlets, hold group seminars, arrange patient-sitting and transportation services. It seems that the patients needed more activity and lacked the ability to perceive suitable alternatives.

Hurvitz, Nathan, "Marital Problems Following Psychotherapy with One Spouse", Journal of Consulting Psychology, Vol. 31, 1967, pp. 38-47.

Therapy with one spouse may complicate, rather than eliminate, marital problems. The therapist may feel that his obligation is to the patient and not to the marriage. The preferable approach may be to treat the couple as a unit and involve both partners in the therapy. This approach regards the spouses as interacting members of a social system within which they perform their respective roles, and the problems in this system are the result of stresses and strains in their role transactions. The counselor makes each partner aware of their respective part in the interaction process and encourages them to "take the role of the other" to facilitate communication and understanding.

Iowa Agricultural Experiment Station Project 1584, "Functional-Dysfunctional Aspects in Family Dyad Interactinn through the Aging Process Among Iowans".

This study assumed that aging is not only a biological and physiological process, but a social psychological process as well. It focused on the degree of interaction as measured by interaction with children, relatives, participation in activities,etc. The general hypothesis was that chronological age is inversely related to social interaction. This was not confirmed in the majority of cases. Possible limitations of the study were that only male responses were used and the age was handled separately from other possible influencing causes: educational level, community involvement, physical health, etc.

Kosa, John; Alpert, Joel J.M.; Pickering, Ruth and Haggerty, Robert J., "Crisis and Stress in Family Life: Re-examination of Concepts", Wisconsin Sociology, Vol 4, 1965.

This paper formulates the theory that crisis and chronic stress are meaningful parts of the dynamic process of family life. It defines stress as psychological in nature and internal in origin, while crisis is a dramatic episode in which external factors of etiology loom large. The interplay of factual and perceptual elements expains the occurance of crisis. Both are critical episodes which disturb the regular functioning of the family because they cannot be

satisfactorily handled with the regular coping processes used with other anxiety provoking episodes. Proper understanding of crisis and stress requires that they should be investigated against the background of daily family life and should be placed meaningfully among the other episodes of family life.

Leik, Robert K. and Northwood, L.K., "The Classification of Family Interaction Problems for Treatment Purposes", Journal of Marriage and the Family, Vol. XXVI, No. 3, August 1964.

If many family problems are the result of faulty group processes, then treatment should attempt to develop more adequate family interaction patterns. To assist the counselor, this paper has classified family problems according to the motivations of the individual members. Different motivations imply different types of treatment which in turn demand appropriate structuring of the counseling sessions. In contrast to other classification schemes, this paper relates treatment procedures directly to the classification category. It suggests that counselors begin with improving communication, then fact finding, and then move to the more difficult and emotional value conflicts.

Leik, Robert K. and Northwood, Lawrence K., "Improving Family Guidance through the Small Group Experimental Laboratory", Social Work, Vol. 9, October 1964,

There has been some use of the small group experimental laboratory to investigate the family group and family counseling. However, because of the difficulties in using families for experimental work, there has been a tendency to assume transferability of principles gained from non-family group experiments. For example, the idea, growing out of ad hoc group research, that there are separate tasks versus emotional leadership roles, has been transferred to the family area as a statement that husbands are the task specialists for the family and wives the social-emotional specialists. Heiss, however, found that as intimacy increased, the differentiation disappeared. The suggestion is that the laboratory is capable of discovering many things about family interaction if in fact families are under study.

Family problems may be manifestations of individual disorders, or the result of inadequate group properties, even though the personalities may be adequate. Research was cited which concluded that the imposition of non-adaptable behavior by one member of a pair produced a significant reduction in adaptability of the partner. Observation of interaction in "problem families" would permit specification of the extent to which therapy should be directed toward the group as a whole rather than toward its individual members.

Three potential uses of the small group laboratory for family counseling and guidance are (1) contributing to the general principles to guide counseling and guidance personnel, (2) providing a diagnostic vehicle for a given case, and (3) evaluating procedures used during treatment.

Litman, Theodore J., "The Family and Physical Rehabilitation", Journal of Chronic Disease, Vol. 19, 1966, pp. 211-217.

A study of 100 disabled patients undergoing treatment revealed no significant relationship between the degree of family integration and success of rehabilitation. There were implications that the family would play a more crucial part after the patient's discharge because then the family could no longer share or abrogate their responsibility. Since the family is an organized system of reciprocal role relations, therapy may be enhanced, or at least made more relevant, if conceived in terms of re-entry into this established constellation rather than as an individual or personal matter.

Ludwig, Edward G. and Collette, John, "Disability, Dependance and Conjugal Roles", Journal of Marriage and the Family, November 1969.

This study attempted to discover the effects on a family of the disablement of the working husband. Subjects were selected from applicants for Social Security disability benefits in central Ohio. In one group of families, the husbands were dependant on their wives in ADL activities; in the other, the husbands were independant. The groups were similar in age and income distribution. It was found that dependant husbands less frequently expressed strict role segregation or role rigidity--and less often had control of major decision making. The families with dependant husbands spent more time together and less with friends or relatives after the onset of disability. The authors conclude that these findings are a result of the dependancy factor, and not merely the result of the physical limitations of the husbands.

Stein, Joan W., The Family as a Unit of Study and Treatment, monograph one, Region IX, Rehabilitation Research Institute, University of Washington, 1969.

The book begins with a historical view of the concept of the family as the unit of study and treatment. A chapter is devoted to eact of three major approaches to family therapy: the psychoanalytic, the integrative, and the communicative-interactive. Each chapter outlines the major concepts underlying that approach, then explores the implications for, and applications to, the therapeutic situation. The appendix contains a sample (selected from the literature) of the types of situations or problems that are indicators or contra-indicators for family therapy.

Stuckert, Robert P., "Role Perception and Marital Satisfaction -- A Configurational Approach", Marriage and Family Living. Vol. 25, November 1963.

The author investigates the relationship between the accuracy with which a recently married person perceives the role expectations of his spouse and the degree of marital satisfaction. For wives, the dominant factor associated with marital satisfaction is the accuracy with which they perceive their husband's expectations. For the husbands, the actual similarity between their concepts and those of their wife is the most important factor. The data supports the

thesis that the husband's role definitions and expectations may be more important to the early success of a marriage than the wife's. Since the American culture defines the husband as the dominant spouse, it is the wife who must be prepared to make the greater adjustment.

Tharp, Roland and Otis, Gerald, "Toward a Theory for Therapeutic Intervention in Families", Journal of Consulting Psychology, Vol. 30, No. 5, 1966, pp. 426-434.

A healthy self-concept is dependent on the satisfactory performance of reciprocal roles. The inability to maintain satisfying reciprocal role relationships with others can produce conflict, negative self or other evaluations, and psychopathology. In the family situation, there are five general role categories: solidarity, sexuality, internal instrumentality, external relations and division of responsibility. Within any of these categories discrepancies between actual and expected behavior can lead to negative self-evaluation and subsequent attempts to re-define the role pattern to allow for more positive self-evaluation. Therapists can intervene to help the family members recognize the existing role pattern and adjust as it is necessary. Such interventions are more effective in the more concrete categories of internal instrumentality, external relations and division of responsibility than in the more complex areas of solidarity and sexuality. These latter two may resolve themselves if other frictions are eliminated.

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STROKE - CEREBROVASCULAR DISEASE

Artes, Richard H., A Study of Family Problems as Identified and Evaluated by the Wives of Stroke Patients, Doctoral Dissertation, University of Iowa, 1967.

Extensive interviews with wives of 65 former stroke patients showed problems of health and physical care were considered to be the most difficult. Problems of behavior (psycho-social problems) and troubles with communication followed close behind with the wives of aphasics seeing communication as more of a problem than wives of non-aphasics. However, all families reported a decrease in verbal output following stroke, even when aphasia was not present. The concern with physical problems was not related to the extent of disability, and most husbands scored semi-dependent to completely independent in Maryland Disability Index. However, very few of the men had returned to work, took a major share of the housework, or assumed new avocational activities, the most frequent reason given was the physical disability. Economic problems were not seen as a major factor in readjustment process.

Bardach, Joan L., "Psychological Factors in Hemiplegia", Journal of the American Physical Therapy Association, Vol 43, November 1963.

Perceptual factors may influence the behavior of hemiplegic individuals. Perceptual distortions, difficulty in distinguishing foreground from background, difficulty in perceptions of the upright, hearing difficulties or distortions may affect performance of the individual and should not be confused with lack of motivation. The environment should be kept as simple as possible and disturbing elements altered if necessary. Intellectual impairment may also be found, and disturbed notions regarding body image may present problems in physical therapy. Denial, regression, egocentricity and disinhibition may combine with the general effects of old age to complicate the rehabilitation process. The family and patient should be given a realistic picture of what to expect from therapy.

Barrow, J. Gordon, Cary, Freeman H., and Gahimer, Joe E., "Development of a Stroke Program in Georgia", American Journal of Public Health, Vol. 52, No. 4, April 1962, pp. 627-631.

Recognizing that proper follow-up of patients after hospital discharge is essential for optimal rehabilitation, a three-part program was designed. First phase was physician education; second phase, applying rehabilitation to stroke patient; and the third phase was the education of a lay public concerning new developments.

Borden, Walter A., "Psychological Aspects of Stroke: Patient and Family", Annals of Internal Medicine, Vol. 57, October 1962.

More attention should be paid to the emotional reactions engendered by somatic processes such as stroke. Anxiety, dependence, depression and regression are

frequent sequelae to a stroke. Many hospitals and family routines prolong these reactions by treating patients like young children. Long range problems require the ability of family members to adapt and take on new roles. Realistic, short-term goals and group therapy help build patient's confidence and social functioning. One of the prime responsibilities of those having professional contact with patient and family is to educate them in the nature of the illness. This is important if the patient is to control and understand his feelings about the illness. Care should be taken that the treatment does not serve to further isolate the patient from the family unit. Family members should be included as active participants in the treatment program. This serves to unify the family and dissolve any guilt feelings in constructive activity.

Bourestom, Norman C., "Predictors of Long-Term Recovery in Cerebrovascular Disease", Archives of Physical and Medical Rehabilitation, Vol. 48, August 1967, pp. 415-419.

In this study the population consisted of fifty-three hemiplegic patients with a mean age of sixty-four years. Twelve variables were studied for their validity as prognostic indicators. Improvement was measured by scores on a 17 item self-care scale. The six variables selected as predictors of improvement in self-care ability (in order of their correlation with the criterion)were: (1) no history of previous CVA, (2) bowel continence, (3) self-care admission score, (4) bladder continence, (5) systolic blood pressure, (6) time between onset and beginning of rehabilitation. All of the correlations were low, indicating that none of these factors, in itself, is an accurate predictor of improvement. The results highlight the complexity of the prediction problem with this population.

Brown, Thomas S. (et. al.), Social and Demographic Factors Associated with the Effects of Stroke Therapy, Initial Report of the Evaluation of the Stroke Program of the San Antonio Rehabilitation Center, Texas Christian University, Institute of Behavioral Research, June 1969.

Fifty-three independent variables, reflecting social and demographic characteristics of patients, physical and medical history, treatment and symptoms during therapy, social and interpersonal adjustment, were analyzed for possible relationships to therapy outcome. Nineteen appeared to differentiate between slight, moderate and good improvement.

In general, the younger, lower class, female, native born, English speaking patients with no previous CVA's, who possess favorable attitudes toward self, relative financial independence and home ownership, and who received a combination of individual and group therapy fared better.

This was considered as evidence of the importance of ability to relate between patient and staff. The findings also support the place of social and group work in the rehabilitation program.

DeForest, Ralph E., "Proceedings of the National Stroke Congress, October, 1964, Chicago, Illinois", Springfield, Illinois: Charles C. Thomas - Publisher.

The source material covered all problems related to stroke - prevention, epidemiology, care of early stroke patients, long term care and rehabilitation, community planning - presented by personnel in their respective fields.

DeLacato, Carl H., "Hemiplegia and Comcomitant Psychological Phenomena", American Journal of Occupational Therapists, Vol. X, No.4, 1956, Part 1.

Cerebral accidents are often coupled with deep psychological traumas. Rigidity, the seeking of an unchanging and familiar environment, is one way the ego protects itself from unvomfortable or threatening stress. Another is propositionality, a problem of consciousness of movement. The reduction of propositionality is one of the chief functions of the occupational therapist. These phenomena have implications for the therapy program and patients should be dealt with in terms of them.

Dervitz, Hyman L. and Zislis, Jack M., " A Medical Perspective of Physical Therapy and Stroke Rehabilitation," Geriatrics, June, 1970.

Physical Therapy following a stroke is divided into four phases. Phase One: a supporting role during the acute stage when primary emphasis is on saving the patient's life. Phase Two: discussing and implementing a therapy program that will result in the maximum restoration possible. It is important that the patient see a prognostic goal and that this goal is constantly re-evaluated in relation to progress in therapy. Phase Three: family unit planning to smooth the transition from hospital to home and ensure effective carry-over into the home of goals achieved in therapy. Phase Four: followup therapy done in the home environment and referral to other specialized personnel services in the community.

In all of these phases, it is essential that the goals be realistic. Success is not defined as a return to work but as the attainment of optimal functional capacity, re-adjustment to the community, acceptance of his limitations and recognition of his abilities.

Ferree, John W., M.D. and Whitehouse, Frederick A., Ed.D., "Rehabilitation the Adult Cardiac", General Practitioner, Vol. IX, No. 2, pp. 43-48.

This article discusses the role of the family physician, "the most important member of the team," in rehabilitation of the cardiac. The "team" may consist of such professions as: vocational counselors, psychologists, time and motion study engineers, social workers, occupational and physical therapists, and the patients themselves.

The first role is explaination and reassurance, first to the family, then to the patient himself. The dangers of over-protecting the patient are stressed;

he states that "Cardiacs who are not too severely disabled to return to work and who do so with a positive motivation are more likely to improve than deteriorate, provided their work is adjusted within the limits of their physical capacity." He cites as evidence the fact that return to work proved beneficial to recovery in the Work Classification Clinic of the Cleveland Area Heart Society.

The author also states that "selective placement is the key to successful rehabilitation of the individual cardiac."

Haese, Julia B., Trotter, Ann B. and Flynn, Richard T., "Attitudes of Stroke Patients Toward Rehabilitation and Recovery", The American Journal of Occupational Therapy, May-June 1970, Vol. XXIV, No. 4.

Twenty former stroke patients whose stroke had resulted in hemiplegia were interviewed in person on a 60 item questionnaire. The questions were designed to elicit opinions regarding disability and rehabilitation. In general the responses showed that the patients were optimistic about their chances for recovery and satisfied with therapy. They attributed their success in rehabilitation so far to their positive attitude toward treatment. Gains in ambulation and self-care seemed to encourage them most after the stroke. Only a few felt that their status as family member or friend had been damaged by the stroke.

Hurwitz, Milton, M., " A Look Back At Medical Mistakes:'Hopeless' Strokes", Geriatrics, January 1970, Vol. 25, No. 1, pp.48-53.

The importance of early, intensive, restorative measures is underscored by the experience of a 73 year old woman who had a stroke from which she could never recover, but did. However, her attempts at recovery were thwarted at every turn by medical and rehabilitation personnel who refused to believe that her condition could improve. By the time they were convinced, some irreparable deterioration had set in. The question is raised as to whether it is justifiable to give a patient or family a totally hopeless prognosis, and to prescribe a totally passive, supportive therapy rather than try an active, direct therapy.

New, Peter Kong-Ming, "The Support Structure of Heart and Stroke Patients: A Study of the Role of Significant Others in Patient Rehabilitation", Social Science and Medicine, Vol. 2, 1968, pp. 185-200.

The author compares the self-evaluations of the patients with the evaluations of significant others regarding their ability to perform activities of daily living. Eleven items are scored as requiring either no assistance, some assistance or total assistance. When patients see themselves as dependent, there is greater tendency for others to agree, when the patients feel they are well, there is less agreement. This could lead to problems in adjustment for the patient and raises the question: do support personnel help only the highly dependent. Use of Activities of Daily Living to evaluate the patients' recovery process is difficult because such activities measure physiological,

psychological and sociological attributes simultaneously. However how the patient defines his own functioning capacity, regardless of any objective criteria the medical staff might use, will determine what he does.

Olsen, Janice A. and May, Bella J., "Family Education: Necessary Adjunct to Total Stroke Rehabilitation", American Journal of Occupational Therapists, Vol. 20, No. 2, 1966.

Group meetings, featuring films and pamphlets as the basis for discussions are suggested as the most practical way of educating families in basic causes and consequences of strokes. Meetings were held for one to two hours every four to six weeks, with a doctor, therapists and social workers explaining their respective roles in the management of stroke patients. The contact with other families appeared to be beneficial to patients and staff alike.

Policoff, Leonard, "The Philosophy of Stroke Rehabilitation", Geriatrics, Vol. 25, no.3, March 1970, pp. 99-107.

Many studies have shown that with proper rehabilitation 80% of stroke victims can regain self-sufficiency, 30% can return to useful work, and only 20% will require institutionalization. That these predictions are not matched by fact is an indication that for too many victims, rehabilitation is not available.

Medical precautions and procedures that should be taken soon after a stroke are reviewed. Emotional and psychological factors are considered and the importance of the family is emphasized. The transition from the institution to the home and then to the community is seen as the crucial and often neglected part of the total rehabilitation process.

Reynolds, Glenn G., "Problems of Sensorimotor Learning in the Evaluation and Treatment of the Adult Hemiplegic Patient", Rehabilitation Literature, Vol. 20, June 1959.

Proper evaluation of sensory disturbance is necessary to prevent needless waste of time by patient and therapist. The standard muscle test seems inadequate in patients with upper motor neuron lesions with variable degrees of voluntary control to be assessed. In the hemiplegic patient multiple factors defy objective measurement. A new type of two part evaluation has been devised. This testing process could be useful in gaining knowledge of the therapeutic effectiveness of facilitative procedures. More study has to be done before we can say that neuromuscular facilitation is the desired therapeutic procedure in all cases of upper motor neuron disease.

Sett, Ralph F., "Simplified Tests for Evaluation of Patients with Chronic Illness (Cerebrovascular Accidents)", American Geriatric Society Journal, Vol. 11, 1963, pp. 1095-1103.

A short objective scale for evaluating patients in areas of ambulation, self-care and communication was developed. Test items, scoring procedures and a discussion of the problems encountered in the development of the form are included. The simplified test compared favorably to the larger, more complicated tests currently in use.

Shanan, Joel, Cohen, Margolith, Adler, Emil, "Intellectual Functioning in Hemiplegic Patients after Cerebrovascular Accidents", The Journal of Nervous and Mental Disease, Vol.143, No. 2, 1966.

Forty hemiplegic subjects were compared to 30 control subjects on the basis of intellectual functioning. The CVA caused a drop in performance particularly on the non-verbal tests (no aphasics in the sample) but the effect seemed to vary according to the age, sex and education of the patient. The authors suggest that in addition to the impairment of specific intellectual functions, the CVA leads to a change in the organization and integration of mental abilities. Thus rehabilitation should focus on compensating for changes in the overall organization of abilities rather than a specific physical task.

Ullman, Montague, Behavioral Changes in Patients Following Strokes, Publication #479, American Lecture Series, Springfield Illinois: Charles C. Thomas, Publisher, 1962.

Clinical material illustrative of some of the critical points of the disease process is presented and the psychiatric implications of this data are discussed. The symptomatology of stroke patients covers a wide spectrum of possible behavioral manifestations, and this book attempts to present a sampling of the variety that do occur. A more inclusive account of the psychological problems and reactions is not yet possible. Some of the specific subjects considered are: relation of stress to occurrence of stroke; early defensive and adaptive responses of the patient; anxieties of the acute phase; depressive reactions. The author calls for increased psychiatric intervention at critical points in the patients' rehabilitation.

Whitehouse, Elizabeth S., There's Always More, Valley Forge, Pennsylvania: Judson Press, 1968.

The book is the author's personal account of the effects of a severe stroke. It describes problems occurring during different phases of recovery and how the author solved them. It discusses the impersonality of rehabilitation program and the effect it has on the client.

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AUTHOR INDEX

Author	Page(s)
Adler, Emil	30
Advisory Council National Institute of Neurological Disease	46
Anderson, J.S.	34
Arffa, M.S.	47
Alpert, Joel J.M.	21
American Heart Association	5,6,7,33,47,51
American and Wisconsin Heart Association	9
American Medical Association	6
Arnold, Mary F.	21,43
Artes, Richard H.	25,46,47
Badgley, R.	41
Baker, Robert	52
Ballweg, Joan A.	17,41
Bardach, Fr. John L.	25,47
Barker, R.G.	34
Barrow, J.Gordon	25,47
Barry, John R.	14,34
Bauder, W.W.	41
Bauman, B.O.	36
Becker, A.	34
Belknap, Elston L.	50
Bell, Gerald D.	14,34
Bell, John E. Ed.D.	41
Blood, Robert O.	17,41
Boldein, George	32
Borden, Walter A.	25,47
Bourestrom, Norman C.	26,47
Boyle, R.W.	47
Breedlove, James L. D.S.W.	34
Brighouse, G.	34
Brodie	34
Brodsky, Carol M.	17,41
Brown, G. W.	41,45
Brown, J. R.	34
Brown, M. E.	52
Brown, Thomas S.	14,26,34,47
Bruett, Terrill L.B.S.	34
Brunnstrom, S.	47
Buchwald, E.	34
Buck, McKenzie	47,52
Buck, Pearl S.	10,31
Buerkle, J. V.	41
Burchinal, L. G.	41
Burdge, Rabel	15,34
Buric, O.	41
Bursten, B.	41
Burton, Genevieve, Ed.D.	41
Busse, Ewald W. M.D.	31
Buxbaum, Joan	13,33
Cannell, C. F.	34
Cantoni, Louis J.	35
Carroll, Douglas M.D.	47
Carroll, E. J. M.D.	41
Cary, Freemen H.	25
Cassel, John	15,35
Center for Mass Communication	7
Centers, Richard	18,41
Chandler, T.	48
Christensen, Harold T.	41
Christopherson, Victor A.	18,41,42
Cockerill, E.	52
Cohen, Margolith	30
Collette, John	23,44
Covalt, N.	48
Cowgill, Donald O.	10,31
Cruickshank, W.W.	35
Cutler	42
Dacso, M.M.	31
Davis, Allan E.	48
DeForest, Ralph E.	27,48
DeLacato, Carl H.	27,48
Dembo, T.	35
Dennerll, R.D.	35
Derek, L.P.	34
Derman, Sheila	13,33
Dervitz, Hyman L.	27,48
Deutsch, Cynthia P.	18,42
Diller, Leonard	52,53
Dinnerstein, A.J.	35
Donahue, Wilma Ph.D.	42
Dorman	48
Dow	39
Duckworth, Grace L.	19,42
Dunteman, George H.	14,34
Dyer, William G.	19,42
Eckstrom, P.T.	48
Farber, Bernard	18
Feldman, D.J.	48

AUTHOR INDEX - Continued

Author	Page(s)
Feldman, Marvin J.	20,42
Felton, Jean S.	35
Ferguson, M.	35
Ferree, John W. M.D.	27,48
Ferreira, Antonio J.	46
Fey, William F.	15,35
Fields, William S. M.D.	48
Fine, Herbert L.	49
Fischer, H.K.J.	48
Fisher, M.	52
Flynn, Richard T.	28
Freeman, H.	35
Friedman, Alfred S.	20,42
Gahimer, Joe E.	25
Garrett, J. F.	35
Gebbard, M.E.	35
Geismar	42
Gelfand, D.	35
Gellman, W.	35
Gibbons, J.P.	31
Gibson	42
Given, Arno	48
Goffman, E.	36
Goldston, Judith A.	18
Golodetz, Arnold M.D.	35
Goodstein, Leonard D.	10,31
Gordon, Edward E.	31,48,52
Gossett, H.	52
Grossman, M.	36
Guttman, L.	42
Haber, Lawrence D.	31
Haese, Julia B.	28,48
Haggerty, Robert J. M.D.	21,42
Hagle, Alfred	36
Handel, Gerald	43
Hanson, W.R.	43
Haskelkorn, F.	36
Heer, David M.	20,43
Henry, W.E.	31
Herring, Marjorie B.	50
Hink, Douglas L.	21,31,43
Holley, Lydia S	36
Hollingshead, August B. Ph.D.	36
Hoops, H. Ray	33
Horwitz, B.	33
Hossack, J.	36
Howard, J.A.	49
Hurvitz, Nathan	21,43
Hurwitz, Milton M.	28,49
Hutchison, G. B.	36
Illinois State Medical Society	8
Institute of Physical Medicine and Rehabilitation	36,38
Iowa Agricultural Experiment Station Project 1584	43
Iseri, Lloyd T.	49
Ismail, H.	49
Iversen, I. A.	39
Jackson, D.D. M.D.	43
Jaques, M.E.	36
Javelin, M.	31
Johannsen, W.J.	49
Kalish, Richard A.	31
Kaplan, D.M.	44
Kassebaum, G.	36
Kasten, J.	39
Kaswan, J.W.	43
Katz, A.H.	36
Katz, S.	31
Kelman, H.R.	36,37
Kelz, James W.	50
Kenny Rehabilitation Institute	49
Kenyon, V. G.	34
Keslinger, F.N.	37
Kessler Institute for Rehabilitation	49
Kirkpatrick, M.	37
Klein, M.W.	37
Klieger, Philip, M.D.	49
Knapp, M.E.	49
Kohn, Kate H.	48
Komarovsky, Mirra	43
Kornbluh, Joyce M.A.	42
Kosa, John L.	21,43
Koski, Carl	33
Kotlar, S.L.	43
Krause, Merton S. Ph.D.	44
Kuhn, Robert	52
Kutner, B.	37,38,44,45
Langsley, D.G.	44
Lavin, Eleanor	49
Lee, P.R.	49

AUTHOR INDEX - Continued

Author	Page(s)
Leik, Robert K.	22,44
Leshner, Martin	49
Levine, E. S.	35
Levinger, G.	44
Lidz, T.	44
Linn, Margaret W. M.S.S.W.	37
Litman, Theodore J.	23,44
Litvak, Eugene	44
Luckey	53
Ludwig, Edward G.	23,44
Ludwig	42
Lugar, Owen	50
Madison, Harry L.	50
Mainland, M.B.	37
Manaster, Albert	13
March of Dimes	7
Margolin, Reuben J.	32
Margolis, D.	52
Martin, Blanche	33
Maryland Disability Index	37
Masterman, L.E.	37
Mattingly, C.	52
May, Bella J.	29,50
McCann, C.B.	32
McCarthy, D.	32
McMahon, A.W.	39
Menninger, K.A.	37
Meyeroff, B.	43
Meyerson, L.	37
Michael Reese Hospital and Medical Center, Baylor University	7
Michel, A.	44
Michels, E.	50
Miers, E.S.	37
Milikan, C.	52
Miller, Daniel R.	44
Mitchell, H.E.	44
Monsees, A.	50
Moskowitz, E.	32
Motion Picture Library AMA	7
Motz, A.B.	44
Muller, J.	37
Murstein, Bernard	44
Myerhoff, B.	43
Nash, Marygold V.	16,37
National Institute of Neurological Diseases and Blindness	50
National Recreation Association	38
National Society for Crippled Children and Adults Publication	38
Neugarten, Bernice L.	11,32
New, Peter Kong-ming	28,50
Newman, Julia	35
Newman, L.B.	50
Nolfi, Mary	45
Northwood, Lawrence K.	22,44
Nye, Ivan	40
Ohio State University	9
Oldham, P.D.	38
Olen, A.P.	50
Olsen, Janice A.	29,50
Otis, Gerald D.	24,46
Overs, Robert P. Ph.D.	34,50
Page, I. H.	50
Palmer, Charles	38
Parsons, T.	38,45
Peterson, J.C.	50
Peterson, Paul Q.	38
Philips, Bernard A.	32
Phillips, Bernard S.	11
Phillips, Derek L.	14
Phillips, R.	35
Pickering, Ruth	21
Policoff, Leonard	29,50
Pollak, Otto	45
Poor, Lucille J.	38
Posman, H.	38
Poulson, J.	45
Power, Lawrence M.D.	42
Prior, Margaret	52
Psychological Exploration Films	6
Rae, J.W.	32
Raven, Bertram H.	18,41
Reeves, L.E. III	50
Reid, M.	47
Reisner, W. L.	51
Research Training Programs in Psychology	51
Reynolds, Glenn G.	29,51
Richter, Otto	3[illegible]
Riley, M.W.	3[illegible]
Ritchie, D.	5[illegible]
Rodman, Hyman	45

AUTHOR INDEX - Continued

Author	Page(s)
Rodrigues, Aroldo	18,41
Roen, Sheldon R.Ph.D.	38
Rogoff, Joseph B.	51
Rolnick, Michael	33
Rosenberg, George S.	32
Rosenstock, F.	38,45
Rosenthal, A.M.	38
Rotter, J.B.	39
Rusk, Howard A.	33
Rutter, M.	41,45
Ryle, Anthony	45
Sarno, John E.	51
Sarno, M.T.	33,51
Scanzoni, John	45
Schoening, H.A.	39
Schull, E.	39
Schuell, H.	33
Sett, Ralph F.	29,51
Shahnazarian, K.	51
Shanan, Joel	30,51
Shapiro, N.L.	39
Shaw, M.E.	39
Sheps, Cecile G.	39
Siekert, R.G.	51
Siller, J.	39
Simmons, D.	35
Simpson, David H.	49
Sirjamaki, John	45
Sokolow, Jack M.D.	39
Sommerville, J.G.	51
Spencer, William A. M.D.	48
Sprey, Jetse	45
Starkey, Pearl Davidoff	16,39
Stein, Joan W.	23,45
Stewart, K.	38
Straus, A.B.	51
Straus, Murry A.	45
Strean, Herbert S.	39
Stuckert, Robert P.	23,45
Suchman, E.A.	39
Sullivan, Richard A.	39
Sussman, Marvin B.	46
Swanson, Guy E.	44
Switzer, M.E.	39
Taylor, M.L.	33,51
Teed, Genevieve B.A.	40
Tharp, Roland G.	24,46
Thomas, Edwin,	39
Thomas	39
Trotter, Ann B.	28
Twente, Esther E.	32
Ullman, Montague M.D.	30,52
University of Pittsburgh Research Project	40
U.S. Department of HEW	32,39,51,52
U.S. Public Health Service Films	8
U.S. Public Health Service Publications	52
U.S. Public Health Service and National Educational TV and Radio	8
U.S. Veterans Administration	7,8,9
Van Buren, James K.	52
Viscardi, Henry	40
Vocational Rehabilitation Administration	53
Wallace, D. C.	53
Wayne State University	7
Webb, Marvin W.	14,34
Weinberg, Joseph	53
Weiss, H.	48
Wepman, Joseph M. Ph.D.	33
White, P.D.	52
Whitehouse, Elizabeth	30,53
Whitehouse, Frederick A. Ed.D	27,48,52,53
Wilson, W. J.	40
Winter, William	46
Winterbottom, Marian R.	40
Wolfe, Donald M.	117
Wolfe, Samuel M.D.	40
Wolff, Kurt M.D.	12,32
Wood, N.E.	33
Wright	53
Wright, Beatrice A.	40
Wright, J.M.	39
Wu, Y. C. Ph.D.	40
Wylie, C. M.	53
Wynne, L.D.	46
Yale University Studies in Marriage and the Family	46

AUTHOR INDEX - Continued

Author	Page(s)
Yarrow, M.	46
Youmans, E. Grant	12, 32
Zbrowski, M.	40
Zecevic, A.	41
Zislis, Jack M.	27, 48
Zola, K.	40
Zung, William M.D.	12, 32

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PROJECT REPORT INDEX

RD	Title	Page
146.01	Results of a Rehabilitation Program for Geriatric Patients in a County Hospital	32
168.00	The Development of the Language Modalities Test for Aphasia	33
244	Blocks to the Employment of the Paraplegic	35
755	Role Modifications of the Disabled Male with Implications for Counseling	18,42
0761.04	Speech Problems in Hemiplegic Patients	51
1462	Cardiovascular Problems in Rehabilitation of Hemiplegic Patients	49
1757.00	Preliminary Results of a Predictor Study in Stroke	47
2131.00	Speech Therapy and Language Recovery in Severe Aphasia	33
2147.02	Stroke Patients in Nursing Homes	47
2176	Conference on Research Needs in Rehabilitation of Patients with Stroke	48
2537.03	A Critical Review of 12 ADL Scales	34
2699.01	Restorative Medicine in Geriatrics	31
RH-2	Social and Demographic Factors Associated with Effects of Stroke Therapy	26,47

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8. Paid Domestic Work for the Trainable Retarded Girl: A Pilot Project, Robert P. Overs, Ph.D., Elizabeth Holmes and Diane McFatridge
This reports the results of brief training of four mentally retarded adolescent girls in household tasks. It compared observed performance with measured intelligence. It includes a job task breakdown and safety skills check list for each of 12 household tasks. There is also an extensive review of the literature and annotated bibliography relevant to the education, training and placement of retarded individuals at the trainable level. 105 pp. + biblio., author and subject index.

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9. Rehabilitation and the Disadvantaged: Annotated Bibliography, 1968-1970, Ann B. Trotter, Ph.D., John T. Dunn, Joav Gozali, Ph.D.

Prepared for the use of rehabilitation counselors, students and other rehabilitation personnel. Includes selections on the general background of many of the disadvantaged, the nature of the counseling relationship involving a person from a disadvantaged or culturally different background, rehabilitation efforts to employ and train the disadvantaged client and attitudes of disadvantaged youth and education of the disadvantaged. 83 annotations, 44 pp. + author index and subject index.

10. A Prevocational and Social Adjustment Program for Educable Retarded Adolescents: A Pilot Project, Vernon Beedy, Barbara Book, Diane McFatridge, and Katherine Novak.

Reports on a two-month vocational orientation and training program for 11 educable retarded adolescents, aged 16-20. The vocational orientation included 11 vocational films and 12 vocational tours. Changes in clients' expressed vocational interests and vocational placement outcome are reported. Program also included vocationally related remedial education and maximum parental involvement, via social worker home visits. 45 pp + bibliography, lists of films and instructional materials used, author and subject indexes.

11. Employment and Other Outcomes After a Vocational Program in a Rehabilitation Center, Robert P. Overs, Ph. D.

This is a structured interview study of a 20% random sample consisting of 148 clients interviewed a year after leaving a rehabilitation center vocational program. Relates employment outcome to age, marital status, impairments, education, race, social class, program completion, attendance and punctuality.

Gives clients' occupational distribution in the work force and data-people-things analysis of positions held. Describes client job hunting methods, job satisfaction, reasons for leaving employment, living arrangements, sources of income, support and dependency patterns, avocational participation and evaluation of rehabilitation experiences.

Includes quantitive summary of 76 followup studies completed between 1957 and 1970.

154 pages with 85 page narrative, 10 page summary with implications, 77 tables, 118 item bibliography, 35 page appendix, author, subject and RSA project number indexes.

12. Educating Stroke Patient Families, Robert P. Overs, Ph.D. and John R. Healy.

This is the final report of SRS Grant No. RD-2537 (new numbering system 15-P-55211/5-03) and describes a four year project, of which two years were an intensive counseling/casework demonstration with stroke patients and their families. Patients were alternately assigned to an experimental and control group and only the experimental group received intensive counseling. A comprehensive followup of 88 families measured differences between the groups on a newly constructed activities of daily living inventory, comparisons on performance of household tasks and extent of avocational activities, attitudes and changes in family roles. The report is in three volumes and includes a report on the outcome of the demonstration, extensive material on attitudes, performance of household tasks and family roles. Volume II includes descriptions of measuring instruments developed. Volume III is comprised of an annotated bibliography of 26 movies about strokes, an annotated bibliography of stroke related publications and a 316 entry regular bibliography.